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Small Closed Virtual Communities

Case: Power and Support from the Net
Rehabilitation courses for people with multiple sclerosis

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ABSTRACT

Multiple sclerosis (MS) is a quite unknown and often a scary disease. However, it is one of the most common diseases of the central nervous system in Finland with approximately seven thousand (7.000) out of 5,2 million Finnish people suffering from it. A smooth rehabilitation for people suffering from MS – a long-term progressive neurological disease is essential to obtain information on the disease and to adapt to it. For MS patients, it is important that the rehabilitation of MS should encourage their autonomy, give them empowerment and social capital as well as improve their quality of life. The rehabilitation methods available to MS patients have traditionally been face-to-face courses and personal physiotherapy. More recently, the Internet has enabled some forms of on-line rehabilitation. Whilst the novelty of rehabilitation courses facilitated by the Internet technology is attractive for the participation factor, the studies on rehabilitation on the Internet are still a few. Nevertheless, rehabilitation studies are important for both practitioners and scientists.

The initial objective of this study comes from practice and it is to find the answer to the research question: Is the Internet a feasible tool for rehabilitation courses for people who suffer from MS? Further on a question was asked about the possibility of an Internet course as a trigger for a long-term virtual community. The study is multidisciplinary with Information and Communication Technology (ICT) as its main discipline, but it also involves Social Psychology concerning matters of rehabilitation and Medicine concerning specialized knowledge on MS. During the study process, sociability and socio-technical capital were discovered as main attributes and vital parts of rehabilitation.

The study process comprised of a case study of two Internet-based rehabilitation courses for people with MS arranged by the Finnish MS Society's Outpatient Rehabilitation Unit. The particular study was constructed from the actual course cases to form a longitudinal study, where the focus was on the concept of the virtual

community and especially on the concept of the sociability that existed among the participants during the courses.

This study offers new information concerning the descriptions of the courses, the scenario of a course as a trigger for a long-term virtual community, the model of a course based on this scenario, and finally it offers a suggestion of applying the possibilities of new Web 2.0 based technology on a course. The results of the study show that Internet rehabilitation courses might be feasible as part of MS patients' rehabilitation with some reservations. On the one hand, this study confirms results of previous studies on virtual communities in health care, i.e. on support and trust and on the social importance of the community. On the other hand though, it contradicts other studies with very different results on anonymity by emphasizing the importance of the participants knowing each other personally. Because this study covers only two cases, more research is needed to confirm the first results and to discover the reasons for emphasizing the importance of personal acquaintance versus anonymity, since both are featured in a number of case studies regarding interaction in the virtual communities.

Keywords: multiple sclerosis (MS), rehabilitation, peer support, sociability, socio-technical capital, virtual community.

TIIVISTELMÄ

MS-tauti on melko vähän tunnettu ja usein pelkoakin herättävä sairaus. Se on kuitenkin yksi yleisimmin esiintyvistä keskushermoston sairauksista, jota Suomessa sairastaa noin 7.000 henkilöä. Kuntoutus on tätä pitkäkestoista ja parantumatonta neurologista sairautta poteville olennainen keino saada tietoa sairaudesta ja sen hoitokeinoista, parantaa sairastuneiden elämänlaatua ja sopeutua sairauden aiheuttamaan epävarmuuteen. MS-taudin kuntoutusmenetelminä ovat perinteisesti olleet kasvotusten tapahtuneet kuntoutus- ja sopeutumisvalmennuskurssit sekä fysioterapia. Viime aikoina Internet on tuonut MS-kuntoutukseen uusia mahdollisuuksia. Vaikka erilaisia verkkoyhteisöjä onkin tutkittu paljon, verkkokuntoutuksen tutkiminen on vielä vähäistä, ja tällä tutkimuksella pyritään tuomaan uusia näkökulmia sekä tutkijoille että käytännön tekijöille.

Tutkimuksen tavoitteena on selvittää Internetin soveltuvuutta MS-taudin kuntoutuskurssien välineenä. Lisäksi tutkimuksen aikana heräsi kysymys kuntoutuskurssien mahdollisuudesta pitkäaikaisten verkkoyhteisöjen alullepanijoina. Tutkimuskohteena oli kaksi Suomen MS-liitto ry:n Avokuntoutusyksikkö Aksonin järjestämää Internetissä toiminutta, kuntoutuksellista Verkosta voimaa ja tukea - kurssia, joiden tarkoituksena oli tarjota lähimenneisyydessä MS-diagnoosin saaneille keskustelufoorumi ja edesauttaa osallistujien sopeutumista uuteen elämäntilanteeseen. Ensimmäinen kurssi toteutettiin ajalla marraskuu 2005 - elokuu 2006 ja toinen kurssi ajalla lokakuu 2006 – huhtikuu 2007. Kurssit olivat suljettuja, ja kummallakin kurssilla oli kymmenen osanottajaa sekä kaksi ohjaajaa. Kurssit aloitettiin ja päätettiin yhteisellä tapaamisella, ja kurssin aikainen kommunikointi tapahtui pelkästään Internetissä, Nettineuvola – keskusteluohjelman välityksellä.

Tutkimus on teoriaa testaava tapaustutkimus. Päätieteenalana on informaatioteknologia, jossa verkkoyhteisöjä tutkitaan Internetin ja teknologian näkökulmasta. MS tuo tutkimukseen lääketieteen, ja kuntoutus sekä yhteisöllisyys tuovat sosiaalitieteiden näkökulman. Tutkimuksessa on kyselyjen ja haastattelujen avulla selvitetty Internetin soveltuvuutta pureutumalla verkkoyhteisöjen

käytettävyyteen ja yhteisöllisyyteen. Painopiste on yhteisöllisyyden osatekijöissä: yhteisön tarkoituksessa, yhteisössä mukana olevissa ihmisissä, yhteisön toimintatavoissa ja sekä pohjana olevassa tietotekniikassa. Tutkimuksessa testataan poikittaistutkimuksessa verkkoyhteisöteorian toteutumista käytännön tapauksissa. Lisäksi tutkitaan pitkittäisesti sosioteknisen pääoman kehittymistä kurssiyhteisöissä.

Tutkimustulokset osoittavat, että Internet sopii tietyin rajoituksin MS-taudin kuntoutuskurssien välineeksi. Merkittävää uutta tietoa ovat kurssikuvaukset ja skenaario Internet-kursseista pitkäaikaisten verkkoyhteisöjen alullepanijana sekä ehdotukset Internet- kurssien mallista ja uuden, Web 2.0- perusteisen sosiaalisen median teknologian hyödyntämisestä. Tutkimus vahvistaa aikaisempia terveydenhuollon verkkoyhteisöistä tehtyjä havaintoja, joiden mukaan yhteisöt voivat tarjota tukea ja empatiaa syvän luottamuksen omaavissa yhteisöissä. Yhteisöjä kannattavana voimana on havaittu erityisesti yhteisön jäsenten vahva sitoutuminen yhteisöön. Vastoin monia aikaisempia tutkimuksia tämä tutkimus korostaa kurssien osanottajien henkilökohtaisen tapaamisen merkitystä luottamuksen aikaansaajana ja henkilökohtaisen tuntemisen tärkeyttä verrattuna anonymiteettiin perustuviin keskusteluryhmiin. Käytännön kannalta tutkimus osoittaa että Internet-kursseja kannattaa jatkaa edelleen, ja parhaimmillaan lyhytkestoiset, johdetut kurssit voivat toimia pitkäaikaisten yhteisöjen alullepanijoina. Kurssien onnistuminen tai epäonnistuminen riippuu, ei niinkään tekniikasta tai organisoinnista kuin osanottajista ja kurssiyhteisön tiiviydestä.

Tutkimus tarjoaa uusia tapoja ja käytännön ohjeita MS-potilaiden kuntoutuksen järjestelyssä. Tutkimustulokset ovat hyödynnettävissä, paitsi uusien kuntoutus-menetelmien suunnittelussa MS-potilaille, myös muiden pitkäkestoisten sairauksien, kuten esim. diabetes- tai syöpäpotilaiden kuntoutuksessa. Kaiken kaikkiaan verkkokursseilla ja verkkoyhteisöillä on paljon tarjottavaa lääketieteen ja kuntoutuksen alueella pitkäaikaissairaiden elämisen laadun parantamisessa.

Avainsanat: MS-tauti (MS), kuntoutus, vertaistuki, yhteisöllisyys, sosiotekninen pääoma, verkkoyhteisö.

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The foundations of this dissertation were laid in 1988, when I was diagnosed with Multiple sclerosis – or maybe even some years before when I noticed first strange symptoms of diplopia, seeing everything in two. After the diagnosis, the disease has reminded me of its existence every now and then – sometimes several times a year with relapses that usually have passed, and sometimes there have been years without any symptoms when I have almost forgotten that I have MS. But it existed all the time. In the beginning last decade when I worked in an IT company as a director and felt the disease strengthening its grip, I thought about what would I do if one day I was not able to work anymore? In the autumn 2002, I decided to activate my postgraduate studies and applied for Professor Pertti Järvinen's doctoral seminar in the Department of Computer and Information Sciences at the University of Tampere. The dissertation topic I had in mind, had to do loosely with "something about MS and the use of IT". Professor Järvinen found my topic interesting because of its multidisciplinary nature that included both Information Technology and Medicine and encouraged me to continue.

In 2004, 16 years after the diagnosis, I felt ready to participate in a three-week face-to-face adaptation course for MS patients in Masku Neurological Rehabilitation Center. During the course, I discussed my plans with Ms. Liisa Leiva, the then Managing Director of the Finnish MS Society, and Docent Juhani Ruutiainen, the Medical Director of Masku Neurological Rehabilitation Center, and they informed me about the new ways of rehabilitation of MS patients: the online courses titled "Power and Support from the Net". I greatly appreciate them for informing and inspiring me, and for encouraging me to continue my plans.

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evaluated my research questions and encouraged me with my efforts. Further, I want to thank the course participants who actively answered my questions and interviews. Without their contribution, this dissertation would not have been written.

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CONTENT

LIST OF PUBLICATIONS

The dissertation consists of the following original research papers:

Paper 1:

Power and support from the net – usability and sociability on an Internet-based rehabilitation course for people with multiple sclerosis. International Journal of Web Based Communities, Vol.5, No. 1, 2009, pp. 83-104.

Paper 2:

Similarities and differences of two web courses for people with multiple sclerosis. Proceedings of IADIS WBC 2008, 24. - 26.7.2008, Amsterdam, Netherlands, pp. pp. 169-173.

Paper 3:

A suggestion for a model to an Internet based rehabilitation course for MS diseased. Proceedings of WIS 2008, Well-being in the Information Society, 19. - 21.8.2008, Turku, Finland.

Paper 4:

Socio-technical capital among two virtual communities for people with multiple sclerosis. Proceedings of IADIS ICT, Society, and Human Beings, 21. - 23.6.2009, Algarve, Portugal, pp. 155-162.

1 INTRODUCTION

Rehabilitation for people with a long-term progressive neurological disease, such as Multiple Sclerosis (MS), is essential for the patients to obtain information on the disease and adapt themselves to it. The objective of rehabilitation for MS patients is to encourage their autonomy and to improve their quality of life. The rehabilitation methods offered to MS patients have traditionally been face-to-face courses and personal physiotherapy, but on the 21st century the Internet has also enabled some new forms of rehabilitation on-line. Although different health care discussion and support groups on the Internet are numerous - as early as 2003 there were already 22.000 support groups in the Health & Wellness section (Eysenbach, 2005) - the rehabilitation courses on the Internet are still quite a new phenomena.

The experiences on Internet courses in MS rehabilitation are scarce, and studying the courses can help organizations to arrange them when planning new ways of rehabilitation on the Internet. The focus of this study is the concept of virtual community and especially the concept of sociability, whose emergence among the course participants was studied. The discussion groups on the Internet are widely researched (Preece, 2000; Eysenbach et al., 2004; Li, 2004; Krcmar and Leimeister, 2005 and Sillence et al., 2006), but limiting the scope to the small Internet groups and rehabilitation of MS will offer new perspectives on virtual communities and their feasibility in the area of health care.

The main research problem of this study was to find out *whether the Internet is a feasible tool for rehabilitation courses,* and during the study process emerged a new problem: *whether an Internet course can act as a trigger for a long-term virtual community*.

The feasibility of the Internet for rehabilitation was investigated by looking at two Internet-based courses titled "Power and Support from the net", arranged by the Finnish MS Society, to find out whether the rehabilitation groups would create virtual communities and how the groups worked during the course. The main objectives of the courses were similar: to have an opportunity to exchange and share

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experiences, thoughts and feelings on living with MS; to find answers to the patients' questions from other people in a similar situation; and to obtain information about MS, its cure and rehabilitation. The study is multi-disciplinary: the main discipline is Information and Communication technology (ICT), but it also contains some aspects of Medicine and Social sciences. Multiple Sclerosis brings the view of Medicine whereas rehabilitation and sociability refer to Social Psychology. The study was performed in four phases of which three were theory testing case studies and one a design research. At first I tested Preece's (2000) theory of virtual communities on one course, secondly I compared the similarities and differences between the two courses, thirdly I created a model of an Internet course in a design research, and in the fourth phase I tested the development of socio-technical capital (Resnick, 2002) on the two courses in a longitudinal study.

The results of this investigation confirm the feasibility of the Internet for rehabilitation courses with some restrictions. The courses created virtual communities at least for the limited course time and also triggered long-term communities after the courses. Continuation from a course to a self-directed virtual community created a need to develop a model of an Internet course in which the course was viewed from a technological perspective. This investigation supports many other studies in emphasizing trust and confidentiality as the socio-technical capital that developed among the communities. My study also shows how important the community participants' personal acquaintance with each other was in these cases, when it came to creating a trustful atmosphere.

In Chapter 2, I describe the core concepts of MS and rehabilitation; the concept of a virtual community (VC), focusing on VC as a social concept; VC in health care; and finally VCs as peer support groups. In Chapter 3, I present the context and the research methods used in the study. In Chapter 4, I describe the courses, the phases of the study, the data collection, and the principles of the data analysis. In Chapter 5, I present the descriptions of the papers published: the research problems, research methods and the research results of each paper. In Chapter 6, I present the self-evaluation of the rigor and ethics of the study. In Chapter 7, I present the discussion on the investigation, the implications for science and practice, the reservations of the study and provide some suggestions for future research. Chapter 8 forms the conclusions of the study.

2 THE CORE CONCEPTS

The core concepts chapter describes the most important concepts used in this thesis. The chapter starts with a description of Multiple sclerosis (MS) and its rehabilitation, continues with a description of the concept of virtual community and the concept of socio-technical capital, and ends with some contemplations of theory.

2.1 Multiple sclerosis

Multiple sclerosis (MS) is one of the most common diseases of the central nervous system and causes severe disability in young adults. Today over two million (2.000.000) people around the world (MSIF, 2010a) and in Finland about seven thousand (7.000) people (Ruutiainen, personal communication, 2010) have MS. The term, multiple sclerosis, literally means many scars. MS affects multiple areas of the central nervous system and may therefore produce a diverse range of symptoms. Symptoms may vary widely and include blurred vision, bladder disturbances, cognitive defects, weak limbs, tingling sensations, unsteadiness, fatigue etc. There is no set pattern to MS and everyone with MS has a different set of symptoms, which vary from time to time and may change in severity and duration, even in the same person. For some people, MS is characterized by periods of relapse and remission while for others it has a progressive pattern. It may cause limitations in social and everyday life, and for everyone it makes life unpredictable (MSIF, 2010a).

The cause of MS is not yet known, but a number of researchers all over the world are meticulously putting together the pieces of this complicated puzzle. The damage to myelin in MS may be due to an abnormal response of the body's immune system, which normally defends the body against invading organisms (bacteria and viruses). Many of the characteristics of MS suggest an "auto-immune" disease whereby the body attacks its own cells and tissues, which in the case of MS is myelin.

Researchers do not know what triggers the immune system to attack myelin, but it is thought to be a combination of several factors (MSIF, 2010b).

Although there is no known medical cure for MS, medicine can help to moderate the symptoms and prevent relapses. The efforts to find the cause as well as a method of cure for MS are continuous. The MS diagnosis is usually a big shock for a person because of the frightening reputation of the disease. Yet, there are many methods to help the diseased to adapt themselves to MS and improve their quality of life. Those methods include physiotherapy, providing relevant information on MS, discussions with other people with MS, and actual rehabilitation.

2.2 Rehabilitation

Rehabilitation for people with disabilities is a process aimed at enabling them to reach and maintain their optimal physical, sensory, intellectual, psychological and social functional levels. Rehabilitation provides disabled people with the tools they need to attain independence and self-determination (WHO, 2010). According to Järvikoski (2004), research on rehabilitation in Finland is multidisciplinary but not extensive enough. It can be classified either as research focusing on the practices of rehabilitation or as research for applying theories and methods. According to him, more research on rehabilitation is needed, which also encouraged me to start my investigation.

Rehabilitation is a component of the comprehensive management of MS, which focuses on function, and adds non-pharmacological strategies to patient care. The objectives of rehabilitation for MS patients are to encourage autonomy and to improve the quality of life through goal-oriented programs that directly involve the person with MS in determining treatment priorities (Messmer Uccelli, 2006). Rehabilitation can be medical, such as physiotherapy; outpatient or institutional courses; help aids; social, such as economical benefits of medical and other costs; psychological, such as occupational help; and juridical, such as pension solutions (MS Society, 2010).

The Finnish MS Society is a national non-governmental organization promoting public health and the importance of physical exercise, and influencing decision-makers in social welfare and health sectors in Finland as well as within the

European Union. The Finnish MS Society looks after the interests of people with MS or other progressive diseases of the spinal cord and cerebellum. It constantly monitors events in the Finnish social welfare and health sectors and works for better social justice and equality for its members. One of the main objectives of the MS Society is to maintain the functional capacity of persons with MS. The Masku Neurological Rehabilitation Center offers people with MS and their families a variety of rehabilitation and adaptation training facilities. The Outpatient Rehabilitation Unit arranges courses disseminating primary information throughout Finland. The Unit is experimenting with new open type of group rehabilitation models in cooperation with regional authorities in social welfare and health sectors. The training programs of the Unit include training in ICT, peer support and capacity building for volunteers in local MS Branches. Rehabilitation courses are mostly held as 2 to 3-week sessions requiring personal attendance, and concentrate on physiotherapy and medical issues, as well as on social and judicial matters (MS Society, 2010).

The Outpatient Rehabilitation Unit of the Finnish MS Society arranged in the beginning of 2000's a project titled *Ohjat omiin käsiin* [Running the show] for finding new ways of rehabilitation (Haukka-Wacklin, 2003). As a result of the project, a tutor moderated Internet course was arranged for young mothers with MS, which was the pilot case where Nettineuvola was used as a discussion tool. Because the course proved to be useful complementary service production (Mäenpää, 2004), the MS Society decided to arrange new courses. The courses studied in this investigation are the continuation of the aforementioned process.

2.3 Virtual community

In this section, I describe the theories concerning the concepts of virtual (Rheingold, 1995) or online (Preece, 2000) community and the concept of Electronic Support Group (ESG) (King, 1994). First I will describe the definitions of virtual communities, then I will focus on virtual community as a social concept, and after that I will concentrate on virtual communities in health care and as peer support. The descriptions are mainly in chronological order for showing the time-related development of the concepts.

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2.3.1 Definitions of virtual communities

The views on online or virtual communities in academic research vary widely. One of the first who defined the concept virtual community was H. Rheingold. According to him, "A virtual community is a group of people who may or may not meet another face to face, and who exchange words and ideas though the mediation of computer bulletin boards and networks" (Rheingold, 1994, pp. 57-58). Virtual communities can be seen as worldwide communities where people with common interests, shared goals, activities and governance interact on the Internet (Rheingold, 1995). Types of virtual communities are versatile. They can be work organizational, commercial, educational, technological, and social, or almost any interest groups, or combinations of types. After Rheingold, there have been a plethora of studies in the virtual community area, and I shall refer to some of those in this review.

In the 1990's, some other researchers showed interest in widening the definition of virtual community. Whittaker et al. (1997) presented five core attributes of physical and network communities: 1) Members have a shared goal, interest or need; 2) Members engage in repeated, active participation; 3) Members have access to shared resources; 4) Reciprocity of information, support and services among members is important; and 5) There is a shared context of social conventions, language and protocols. Lazar and Preece (1998) divided online communities into four dimensions: by attributes, by relation to physical communities, by supporting software, and by boundedness. The attributes of a community may include e.g., the goals and topic of interest, the type of activity, the type of interaction, size, the level of support, the level of anonymity, and the type of conventions, language and protocols. The relation to physical communities may require frequent, periodic, or without face-to-face interaction. The supporting software can be e-mail lists, listservs, newsgroups, bulletin boards, Internet-relay chat, team rooms, or Web-based bulletins. The online community can be tightly or loosely bounded to an organization.

In the 2000's, virtual communities have permeated through many areas of society. According to Schubert and Ginsburg (2000), virtual communities describe the union between individuals and organizations who share common values and interests and use electronic media to communicate within a shared semantic space

on a regular basis. Alexander (2002) studied distant learning and virtual organizations and especially how communication via e-mail affects the functioning of virtual or dispersed collaborative teams, and how e-mail communication influences the viability of such teams in telecom or web-based education. Alexander defined virtual organization as a temporary or a permanent collection of interdependent, geographically dispersed individuals or groups from within the same organization or from different organizations, which depend on electronic linking in order to achieve a collective goal. Bieber et al. (2002) defined a virtual community to concern anyone actively interested in or associated with a group formed around a particular domain of interest. The community can be dispersed or local, but it needs electronic connection to support the continuous service strategy of the community.

Preece (2000) categorizes an online community according two main criteria (Table 1): usability and sociability, where good usability is needed for supporting sociability. Usability is concerned with human-computer interaction, and systems with good usability are consistent, controllable and predictable. Sociability is concerned with human-to-human social interaction, where communities with good sociability have unambiguous and supportive social structures. Both categories in Table 1 can be further divided into four sub-categories: First, online community has a shared *purpose*, such as an interest, need, information exchange, or service that provides a reason for the community. One shared purpose gives a reason for the community's existence and reason for its members to belong to the community. Secondly, *people* interact socially as they strive to satisfy their own needs or perform special roles. People communicate with each other socially to reach their needs and to perform their tasks according to their roles. Trust and empathy between the people will encourage the co-operation. Thirdly, online communities have *policies* in the form of tacit assumptions, rituals, protocols, rules, and laws that guide people's interactions. The rules of assuring the privacy and confidentiality create a trustful and secure community. Policies direct interaction and help developing shared language and culture for the community. The fourth attribute needed in an online community is *computer systems*, to support and mediate social interaction and facilitate a sense of togetherness. .

Usability is concerned with human–computer interaction and with developing computer systems to support rapid learning, high skill retention, and low error rates.

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The implication of an online community is that the users are able to communicate with each other, find information, and navigate the community software with ease. Dialog and social interaction support mean support for communication with recognizable icons and visualization. Information design distinguishes between new, old and different types of content. Navigation support means moving around the community, searching messages and moving between the modules. Access means the technical possibility for connection.

Table 1. Preece's (2000) categories on virtual communities

Sociability	Component	Meaning
	Purpose	Interest, need, reason
	People	Interaction, communication, trust and cooperation
	Policies	Rules, laws, trust and security
	Computer systems	Support
Usability	Dialog and social interaction support	Visualization, icons
	Information design	Content types, new and old contents
	Navigation	Moving between modules, searching messages
	Access	Connections

De (2003) defined virtual community as a group where people communicate with each other on the Internet. The most important elements of virtual communities are communication and tool, and they can be categorized further according to the meaning of the community, personal relations, norms, expectations, dependencies and the instance of use. Fernback and Thompson (1995) argued that the most recent communication technology development within the post-industrial era is CMC, Computer-Mediated Communication. Comprised of different systems such as electronic mail, bulletin board systems, and real-time chat services, CMC is both an interpersonal, one-to-one medium of communication and a one-to-many or even a many-to-many form of mass communication.

Li (2004) collected a literature review concerning different definitions of virtual communities. She specifies the differences between virtual communities and virtual groups or teams. Most virtual teams are formed to solve specific problems or tasks, they are organized by specific organizations and they usually end when the task has been performed. The virtual communities focus on a relationship development in

real life, when people with similar interests spontaneously take part in the communities. The virtual communities can exist for a very long time, as long as people with similar interest do not disperse, while virtual groups or virtual teams usually dissolve after the task is finished or the problem is solved. Moreover, some others see a group as a special type of social network – one that is heavily interconnected and clearly bounded (Wellman, 2001), and Whitworth and de Moor (2003) defined virtual community as a socially self-sustaining and continuing group with persisting social practices operating in a common computer-mediated space.

The virtual community technologies presented above are mainly based on the Internet and World Wide Web – the so-called Web 1.0 technology. During the first decade of the 21st Century, new technology, new tools and new ways of communication emerged. Social media and Web 2.0 are new concepts in Web and Internet environments. O'Reilly (2005) suggested that 2001 – the year the dot-com bubble burst – was the year when Web 1.0 came to an end and Web 2.0 was born. According to Ovaska and Leino (2008), "Web 2.0 is a vague concept, considered by many merely a buzzword, but relevant to all working in the fields of interactive technology and user interfaces". New tools, like MySpace.com, YouTube.com, Facebook.com, Twitter.com for everyday computing, and some tools, like PatientsLikeMe.com targeted for various prevalent diseases, have joined the everyday environment of virtual communities. Anyway, a deeper analysis of Web 2.0 tools is left out of this investigation and the cases are based on more traditional Web 1.0 environment – a discussion forum with textual data.

My approach for analyzing virtual community in this thesis is mainly based on Preece's (2000) theory because of its ICT and social perspectives. In spite of the existence of many other virtual community studies (Joinson, 2001; Wellman, 2001; Laister and Kober, 2002; Ridings et al., 2002; Whitworth and de Moor, 2003; Sillence et al., 2006), I considered Preece's theory the best way to approach the problems of this investigation. Its categories created a well-organized structure for the phrasing of the questions, interviews and the description of my investigation.

2.3.2 Virtual community as a social concept

As the previous definitions showed, virtual communities have a strong social dimension. In this section, I concentrate on the social perspective of virtual communities by selecting some examples from literature.

Sennet (1978) studied the concept of community before the age of the Internet and defined it as a set of social relationships that operate within specified boundaries or places. According to Sennet, communities are composed of elements like social interaction, a shared value system and a shared symbol system. The elements constitute the four distinct realms of community: the social, economic, political and cultural. The social realm of community encompasses social interaction, solidarity, and both individual and institutional relations. A community can thus be a traditional face-to-face community or a distant, time and/or place independent electronic community. Also Rheingold (1995) saw virtual communities as social aggregations that emerge from the Internet when a number of people carry on public discussions long enough, with sufficient human feeling to form webs of personal relationships in cyberspace.

Ihanainen (2001) wrote about education in Internet environment in his book, Tietoverkon sielu [The Soul of Data Network]. According to him, networked sociability is a mediated individual notion of sociability. The sociability experience that evolves on the basis of individual views is more sensitive to reshaping and dispending than physical-social sociability experience. Therefore networked sociability is more vulnerable than face-to-face sociability. Moreover, Ihanainen specifies networked sociability that will emerge and come true in a situation where a person meets her or his net partner via computer display, and where they communicate by typing messages, discussions, documents or other texts on display. A person meets by her/himself other people somewhere out there – on the Net.

Ridings et al. (2002) argued that virtual communities are social networks in a virtual space, which bring people together. The binding force of a community is trust, and their study shows that trust is essential for the sustainability of a group and its ability to generate commitment and contribution. However, trust is not essential in all virtual communities. For example, online gaming communities need rules and not trust to function. Järvenpää et al. (2004) wrote about the role and importance of trust in virtual communities concentrating on global virtual teams. They found that

trust may be dependent on the situation or on the conditions where the communities are, and because the virtual communities' states are not stable, trust affects virtual teams differently in different situations.

If we compare virtual communities with real-life communities, we find conflicting characteristics. Virtual communities can work more as an extension to organizations than as their substitute. On one hand virtual communities have been seen to work better in establishing social communications than real-life communities, on the other hand they have been seen to diminish an individual's face-to-face communication and impede real life social contacts (Wellman et al., 1996). Joinson (2001) compared behavior on the Internet vs. behavior in "real life" and his studies indicate that computer-mediated communication may have high levels of self-disclosure in comparison to face-to-face discussion.

According to Wellman (2001), computer networks are inherently social networks, which link people, organizations and knowledge together. They are social institutions that should not be studied in isolation but as integrated into everyday lives. When computer systems connect people and organizations, they form social networks. Wellman argues that the term "groupware" may be misleading, because computer networks support social networks, not groups. A group is only one special type of social network – one that is heavily interconnected and clearly bounded. Often computer networks and social networks work conjointly, with computer networks linking people in social networks and with people bringing their offline situations to bear when they use computer networks to interact. Although the support of collaborative work was the initial purpose of the Internet (both e-mail and the Web), it is an excellent medium for supporting far-flung, intermittent, networked communities.

Whitworth and de Moor (2003) defined virtual community as a socially self-sustaining group with persisting social practices acting in a common computer-mediated space. "Groups are socially self-sustaining when the benefits of social interaction, such as gaining knowledge, making friends, or collective action, make members want to remain in the group for social reasons (p. 32). According to them, to be self-sustaining a community must generate social value for its members. The value is the benefits of social interaction, not the costs. Whitworth et al. (2000) presented a cognitive three-process model of computer-mediated group interaction (CMI). According to them the interaction has three types of influence:

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informational, personal, and normative, and three group purposes: task resolution, interpersonal relationship and group unity. The interaction also creates social norms for the community.

Laister and Kober (2002) used Preece's (2000) categories in studying social aspects of collaborative learning in virtual learning environments. They highlight two general and interrelating requirements of successful online communities: Usability, which focuses on the human-computer interaction, and sociability, which focuses on the social interaction processes. Usability focuses on the software design and good usability signifies low error rates, high productivity, rapid learning, and efficient use. Sociability is conjunct with planning and developing policies, which should support the goals of online communities and be understandable and acceptable to the members of those communities.

2.3.3 Peer support in health related virtual communities

In the context of health, information on health issues can be shared on the Internet, but virtual communities on the Internet often have the function and character of a self-support group. They can be called Electronic Support Groups (ESGs), where, for example, patients with a certain condition or consumers with a common health-related interest exchange information and experiences (King, 1994; Eysenbach, 2005). King was one of the first researchers who investigated ESGs for substance addicts. King had found several advantages in ESGs. Among them is the thoughtfulness of the replies to the common issues that recovering addicts face. The written conversation differs from the spoken one because thoughts can be formed more slowly and edited more carefully. The experiences in written form may seem more powerful and clearer than the spoken messages at meetings. King found a positive correlation between ESG usage rates and results, a reported improvement in recovery, and a positive correlation between membership time and having contacts. It is possible that members who live in isolated rural communities are using ESGs to expand their access to emotional support. King also found a positive correlation between the frequency of advice seeking and the reported improvement in recovery programs (King, 1994).

Eysenbach et al. (2004) collected a systematic review of health related virtual communities and ESGs, and found virtual communities e.g. on depression, social support, health care use, eating disorder, weight loss, diabetes control and smoking cessation. They concentrated on searching for "peer-to-peer only" communities where no health professionals were involved. They found no robust evidence of health benefits of consumer-led peer-to-peer communities. The variation of the interventions was wide, but the effect of online support groups on health related outcomes and healthcare resources use remained unclear.

McDaniel and Stratton (2006) studied the Internet-based smoking cessation programs and found them a promising strategy for reaching smokers worldwide. Internet-based smoking cessation programs can extend the clinical encounter, in essence allowing the provider to offer virtual support to the patient who is attempting to quit smoking. The interactive capabilities of Internet applications show great promise for customizing a smoking cessation plan on-the-fly for individuals seeking support in quitting, but only few websites offer programs that incorporate tailored approaches. Lehto and Oinas-Kukkonen (2009) studied the Web-based alcohol usage interventions for drinkers who would not participate in conventional treatment. They reported that the Web-based alcohol usage interventions vary greatly in level of finesse: some offer static self-help materials, whereas some sites have highly interactive content and persuasive features embedded. They studied the six Web-based alcohol usage interventions, and all the evaluated sites successfully demonstrated trustworthiness, expertise, and surface credibility. Many of the sites were lacking in the social support category. In general, the authors suggest that the persuasive system qualities should be considered concurrently with the feasibility and effectiveness for studying technology-based interventions (Lehto and Oinas-Kukkonen, 2009).

Finn (1999) argued that online groups could provide support for their members when face-to-face groups are not available. The members eliminate barriers related to time and distance, and the advantages are especially important for those whose disabilities make it difficult or impossible to attend a face-to-face group. Online groups offer a greater degree of anonymity than face-to-face groups, and age, gender, race, or physical appearances are of no importance. He also found some disadvantages: little is known about the extent to which members experience harm through negative, hostile or malicious encounters.

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Preece (2000) argues that online patient groups may discuss health-related information to understand better the patients' problems, to acquire information about diseases and treatments, to get support from others, to help fellow sufferers, and so on. Patterson (2000) recognized two types of support groups available on the Internet: peer support groups and counselor-led support groups. Both offer a number of benefits including empathy and support; immediacy; a global community; vast resources in terms of types of treatment methods and sources of additional information; cost-effectiveness in an on-line service; and anonymity. Disability-specific Internet support groups can be helpful to individuals who have less common disabilities, live in rural areas, or have transportation or scheduling problems.

Neal et al. (2006) studied online health communities that provide a means for patients and their families to learn about an illness, to seek and offer support, and to connect with others in similar circumstances. Online health communities are a challenge to design because of the wide variety of their members' medical expertise, health literacy, technology literacy, and the potential severity of problems due to misinformation. They found several situations where online health communities aid patients by enhancing their health literacy, improving their quality of life and decision-making skills – as a result, the patients felt less alone and more empowered.

Sillence et al. (2006) presented factors that were important to health information and online advice services. The users may be influenced by the look and the feel of the site, they may be influenced by the quality of information available on the site, and they may be influenced by the extent to which the advice is personalized to the individual – i.e., the extent to which the advice appears to come from and be directed to similar individuals or those with a shared social identity. Demiris (2006) emphasized virtual communities' ethical challenges including identity and deception, privacy and confidentiality, and technical issues, such as usability and sociability. The communities he investigated were a mix of health care providers, educators, patients and caregivers.

Wald et al. (2007) found out in their studies that the potential advantages of Web-acquired information include helping patients to make informed health care choices, shared decision-making with a collaborative, teamwork approach, a more efficient use of clinical time, an augmentation to physician-provided information, online

support groups, and/or access to patients' own health information. But the misinformation due to the highly variable quality of Web information, the possible exacerbation of socio-economic health disparities, and the shifting of conventional notions of the physician–patient relationship present their own set of challenges for the health care provider.

Cancer patients' situation can be in many aspects compared to that of MS patients. The diagnosis is often a shock, and the need for information on the disease, its symptoms and treatments is great – likewise the need to exchange feelings and experiences with other sufferers is big (Krcmar and Leimeister, 2005). The potentials are up-to-datedness, anonymity and a needs-based coverage of patient information, as well as interactivity, empathy and empowering patients. Emotional integration into a community of peers can mean a) knowing how the other people feel, b) feeling what the other people feel, and c) answering/acting according to this feeling (Arnold et al., 2005). Anonymity within the support group fostered equal participation and allowed the participants of the group to communicate in ways that would have been more difficult in the face-to-face context (Shaw et al., 2000). Josefsson (2003) in her study of Swedish patient online communities identified two important forces: to be informed and to interact with others in a similar situation. Uitterhoeve et al. (2004), Thaxton et al. (2005) and Vilhauer (2009) reported of support for patients with cancer. Their studies showed that the interventions for men with prostate cancer can lead to a pronounced improvement in psychological functioning and may in some instances increase longevity (Thaxton et al., 2005), and that behavior therapy has positive effects on one or more indicators of quality of life of the diseased, for example, it reduces depression (Uitterhoeve et al., 2004). The support groups for cancer patients can also have therapeutic factors, such as group cohesiveness, information exchange, universality, instillation of hope, catharsis, and altruism. However, although participants reported being able to discuss many other concerns freely, they had difficulties with discussing death and dying (Vilhauer 2009).

Hughes et al. (2009) explored kidney disease patients' experiences of receiving individual peer support. They made qualitative telephone interviews with a sample of 20 people who had received peer support. The majority of the respondents were overwhelmingly positive about their experience of peer support and its benefits. They valued peer support because it had given them access to practical information

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about kidney disease, based on lived experience, which helped them reach decisions about treatment. Peer supporters offered the patients' empathy, understanding, confirmation that they were not alone in their suffering, positive role models for coping with treatment for kidney disease, and hope for the future. Peer support helped the patients to adapt to chronic illness by normalizing adherence to demanding treatment regimes and increasing the patients' sense of empowerment and agency.

2.3.4 Peer support for groups with Multiple sclerosis

Aaltola (2006) wrote about Internet discussion forum as peer support for people with MS. The purposes of her study were to determine how the Internet discussion groups provide social and peer support for people with MS and what kind of personal profile these people have. Three thematic areas that describe the type of information and support available to discussion group participants were identified. Those thematic areas were seeking and giving information about MS, the experiences of getting ill, and the experiences of being ill. The thematic area of getting ill included messages on symptoms of MS and on the uncertainty of the diagnosis. The thematic area of being ill included messages on experiences of MS and on the impact of the illness on the patients' lives. The discussion group on the Internet exchanged information, support and sympathy. The results of her study showed that an Internet discussion group might offer useful peer support for an MS patient. The study also described the solutions the participants offered to each other's problems.

   Mohr et al. (2005) studied a skills-based telephone-administered peer support program (TAPS) for MS patients. According to them, the peer-support interventions had not shown any statistically significant or clinically meaningful effect on the quality of life (QOL) or on the depressive symptoms of MS patients. Peer-support interventions for MS patients generally provide support but no skills training. TAPS is a manualized program administered by peer-support counselors diagnosed with MS, with which peer-support counselors teach skills to manage distress and MS symptoms. The study showed that the MS patients had noteworthy

improvement on depression handling, and that the overall quality of their life also improved significantly.

According to Messmer Uccelli et al. (2004) utilizing peers as resources was proposed as an effective means for coping with a stressful life experience and for gaining support from others who shared a common factor. They evaluated the effectiveness of eight weeks of a standard form of peer support in improving quality of life and reducing depressive symptoms in 44 patients with MS. Results showed that support groups did not provide consistent improvement on quality of life or depression for patients with MS, and suggest that patients, who had better mental health, could be at risk for deterioration in support groups.

Paine et al. (2006) studied mutual-aid groups that can provide a context in which people share similar problems, conditions, or concerns, and give and receive support. The members of the two different peer-led mutual-aid groups participated in their study: one group consisted of women with a low-income and the other of people with MS. Results suggest that the leader training was effective in increasing the percentage of disclosures about personal concerns, followed by supportive behavior in the low-income women's group, although the effects did not apply to the MS group.

2.4 Social and socio-technical capital

Socio-technical capital is a concept where social capital and ICT are connected. Social capital has been defined in many ways (Bourdieu, 1983; Coleman, 1988, 1990; Putnam, 1993, 2000; Nahapiet and Ghoshal, 1998; Uphoff, 1999; Ruuskanen, 2001; Preece, 2002). Bourdieu (1983) defined social capital as resources linked to a network of relationships of mutual acquaintance and recognition. Coleman (1988, 1990) and Putnam (1993, 2000) defined social capital as social networks or structures where Coleman emphasized individuals as actors, when Putnam emphasized an organization. Nahapiet and Ghoshal (1998) wrote about social capital, intellectual capital and the organizational advantage. Uphoff (1999) considered the social capital as an asset that yields benefits and analyzes the income stream that flows from social capital as mutually beneficial collective action. Ruuskanen (2001) defined the social capital as social networks, norms and trust that

improve the social interaction between community members and the reconciliation of the operations. Thus social capital strengthens the realization of a person's objectives and the welfare of a community.

Rheingold (1995) was one of the first people to write about virtual communities and social network capital, and Putnam (2000) described computer-mediated communication and the relations connected by computers. Wellman (2001) said that the Internet adds to a person's social capital by increasing contacts with friends and relatives who live either nearby or far away. According to Preece (2002), the glue that holds communities and other social networks together is called social capital. It is a resource that helps a community to sustain. She emphasizes trust as a key factor for developing social capital, and defines social capital as the social equivalent of financial capital.

Huysman and Wulf (2006) wrote an article of IT, social capital and knowledge sharing, and they published a review of applications that are believed to support social capital. They talked about converging social networks and electronic networks as the domain of socio-technique. They emphasized knowledge sharing, and argued the higher the level of social capital, the more (distributed) communities are stimulated to connect and share knowledge. Distributed community members will be more inclined to connect and use electronic networks when they are motivated to share knowledge with others, able to share knowledge and have the opportunity to share knowledge. The driving forces within the key concepts that help communities stay active are mutual trust and recognition by peers, which both indicate a high degree of social capital.

Resnick (2002) defined the concept of socio-technical capital to refer to productive cooperation between social relations and ICT. He listed seven forms of social capital and five types of activities that people who have social capital can do together. According to Resnick, the forms of social capital are communication paths, common knowledge, shared values, collective identity, obligations, roles and norms, and trust. Communication paths enable information sending and receiving. Closed groups and links between group members are essential in creating social capital. Common knowledge can be shared stories or interests, and it can through common understanding help to create emotional support. Shared values help in the emergence of a shared goal and thus they can evoke better co-operation. Collective identity is born when a person feels like she/he belongs to a group and when the

other group members and also outsiders treat a person as a member of the group. The obligations may be explicitly or implicitly acknowledged. In either case, the fulfillment of these obligations will create value for the group in the future. The roles can be pre-defined, like a lecturer and the audience, or they can be built with time. The norms of behavior help people to play their roles. Trust is an expectation that others will act in a way favorable to one's interests, even if they have an opportunity to do otherwise. Trust also colors how an individual interprets the actions of others, so that information from trusted sources is more likely to be heeded and aid from trusted people is more likely to create a sense of emotional support.

According to Resnick, the five types of activities enabled by the forms of social capital are the following: information routing, resource exchange, emotional support, coordination, and collective action. Social capital can facilitate information routing, which in turn can help to highlight important information in a case of information overload, or it can help to bring information for others who are interested in the topics discussed. Social capital can help people to exchange other resources besides information e.g., to exchange goods on the Internet. Social capital makes it easier for people to provide emotional support to each other, as people who know and trust each other are more likely to share personal information. Social capital enables coordination of interdependent actions. For example, in a project, some tasks may need to be completed before others or undertaken simultaneously. Groups of people who have social capital are able to schedule their activities and use resources shared in a way that respects these interdependencies. Finally, social capital can help people overcome dilemmas of collective action.

2.5 Contemplations of theory

When considering the theories to apply in my research, I became acquainted with Gregor's (2002, 2006) categorization of information systems theories. She proposed a taxonomy that classifies information systems theories (Table 2):

- Type I: Theory for Analyzing and Describing
- Type II: Theory for Explaining
- Type III: Theory for Predicting
- Type IV: Theory for Explaining and Predicting
- Type V: Theory for Design and Action.

Table 2. A taxonomy of theory types in IS research (Gregor , 2006)

Theory for	Distinguishing attributes
I. Analyzing and Describing	says what is". The theory does not extend beyond analysis and description. No causal relationships among phenomena are specified and no predictions are made.
II. Explaining	says "what is", "how", "why", "when", "where". The theory provides explanations but does not aim to predict with any precision. There are no testable propositions.
III. Predicting	says "what is" and "what will be". The theory provides predictions and has testable propositions but does not have well-developed justificatory causal explanations.
IV. Explaining and Predicting (EP)	says "what is", "how", "why", "when", "where" and "what will be". Provides predictions and has both testable propositions and causal explanations.
V. Design and action	says "how to do something". The theory gives explicit prescriptions (e.g., methods, techniques, principles of form and function) for constructing an artifact.

According to Gregor, the decision to allocate a theory to one class might not be straightforward, and some judgment may be needed to determine what the primary

goals of a theory are and to which theory type it belongs. She suggests Information Systems (IS) researchers to identify: (i) what theory is composed of in general, and (ii) to analyze the components of their own theory and the theory of others.

My descriptions of Preece's (2000) and Resnick's (2002) theories might be categorized as Gregor's Type I: Theory for Analysis where "The theory does not extend beyond analysis and description. No causal relationships among phenomena are specified and no predictions are made" (Gregor, 2006, p.620). The Type I theory says what is. Later on, the design research part of my investigation might belong to Gregor's Type V: Theory for Design and Action where "The theory gives explicit prescriptions (e.g., methods, techniques, principles of form and function) for constructing an artifact" (Gregor, 2006, p.620). The type V theory says how to do something.

3 RESEARCH APPROACH

The study at hand concentrates on the two Internet-based rehabilitation courses for people with MS. My background is in ICT-related business, which created challenges in the scientific dissection and in choosing a theory for the investigation**.** The objective of the study - the Internet courses as well as the research question, feasibility of the Internet for the courses – came from everyday life. Internet-based rehabilitation courses have a relatively short history and they have not been studied much. According to Eisenhardt (1989), a case study suits especially the situations where the area of study is new with little previous research. Based on these premises, I selected a case study method for my investigation.

I will in this chapter describe the research methods selected. In addition, I present the validity and reliability criteria that I later use in the Self-evaluation of rigor Chapter.

3.1　Research methods

In this section, I describe the research methods selected: case study research and design research, and give the reasons for selecting them.

3.1.1　Case study research

When selecting the research method, case study method became the obvious choice very early on. The topic – Internet rehabilitation courses – and the preliminary research question were suggested by the Finnish MS Society when the first course was about to start. As a researcher, I had to select an outsider's point of view of the course, which was a condition set by the course participants. Thus, it was not possible to select a participatory method.

Eisenhardt (1989), Lee (1989), Klein and Myers (1999), Yin (2003), Järvinen (2004), and Eisenhardt and Graebner (2007) have written about case study research methods. Järvinen (2004) wrote that in a case study the researcher tries to create an image of the world with a certain case at a certain moment.

Yin (1994) defined the case study as a method of choice when the phenomenon under study is not readily distinguishable from its context. According to him, case studies are the preferred strategy when "how" or "why" questions are being posed, when the investigator has little control over events, and when the focus is on a contemporary phenomenon within some real-life context. This can in my study be expressed by how the feasibility or non-feasibility of the Internet is confirmed. Trying to answer the question why this occurs made it possible to classify this study as a case study.

Yin (2003) characterized case studies by 2 x 3 dimensions. A study can be a single case study or it can be a multiple case one. Multiple cases should be selected in a way that they replicate each other. I started by one course, a single case, which was later complemented by another course. According to Yin the studies can also be explanatory, exploratory or descriptive. My study is a descriptive one, which according to Yin presents a complete description of a phenomenon within its context.

The case study research can be either a theory testing or theory creating one (Järvinen, 2004). After orientating myself with literature on online or virtual communities, I found Preece's (2000) theory that extensively described the features of online communities. I decided to test the applicability of her theory in a real life, and thus decided to follow a theory testing method in my study. The seven phases of a theory testing case study are (Järvinen, 2004): 1) Defining the need for the investigation; 2) Selecting the theory; 3) Setting the case; 4) Collecting the data; 5) Analyzing the data; 6) Finding the results and conclusions; and 7) Suggesting discussions and future investigation needs. My study process followed all these phases.

My approach is mainly qualitative, but it also has some quantitative material. Qualitative research does not strive for statistical generalizations but for describing an occasion and understanding a certain function or giving a theoretically reasonable interpretation of an event. A crucial factor in qualitative research is not the size of the research material, but the tenability and the depth of the interpretations (Eskola

and Suoranta, 2005). The material of this two-case study contains data with some quotations from the informants. The story must be connected to the theory to demonstrate the connection between the story and the emergent theory (Eisenhardt and Graebner, 2007).

Järvinen (2010) introduced a new taxonomy for developing and testing theories, where the repetitive node is for re-testing the theory that already survived the original node (Figure 1). Järvinen argued that after a successful re-testing, the theory can continue in other contexts, otherwise it must be corrected and re-tested in another context with the original node. Though Colquitt and Zapata-Phelan (2007) emphasized that replications of previously published work and very incremental research rarely offer enough of a contribution to warrant publication, Berthon et al. (2002) and Järvinen emphasize replications as important components of scientific methods when converting tentative belief to acceptable knowledge. Because of those arguments, I will use this new taxonomy in my research in the phase where I compare the two courses and utilize the results from the first phase.
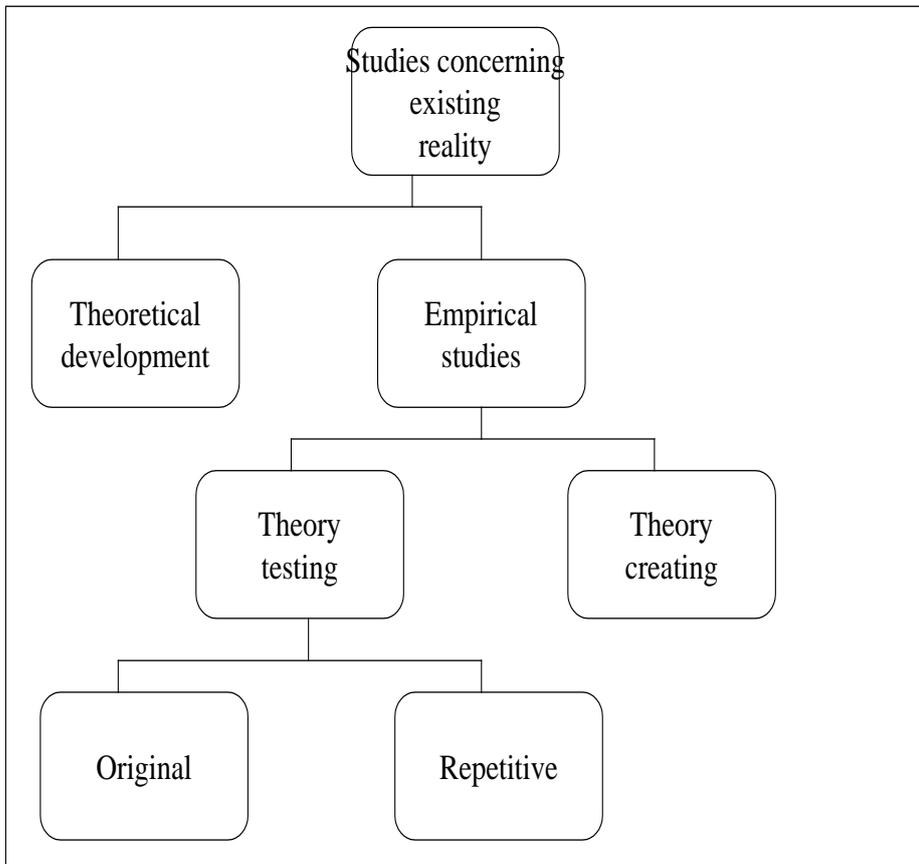
Figure 1. A new taxonomy for developing and testing theories

3.1.2 Design research

After the courses a challenge occurred, when the actual courses ended but the participants wished to continue the discussions on their own. The problem emerged when the possibility to communicate using the Nettineuvola discussion tool was no more available because of contractual reasons. Thus the only way to continue was to use group e-mail. This situation raised a question: Would it be possible to improve the technical environment to enable a better way to continue the discussion forum after the original course? The best way to approach the question seemed to be design research strategy.

Järvinen (2004) argues that when the research question contains the verbs build, improve, extend or introduce, the study belongs to design research. Van Aken (2004) argues that the mission of a design research is to solve improvement and construction problems. Research activities in design research are twofold: build and evaluate. Building is the process of constructing an artifact for a specific purpose; evaluation is the process of determining how well the artifact performs. Design research products are of four types: constructs, models, methods, and instantiations. In design activities, models represent situations as problem and solution statements (March and Smith, 1995). According to Gregor's (2002, 2006) categories, the part of creating a new model for an Internet course in my study can be classified as "Type V: Theory for Design and Action". This theory describes how to do something and it can give explicit prescriptions (e.g., methods, techniques, principles of form and function) for constructing an artifact.

Hevner et al. (2004) gave seven guidelines for design research and they are:

1. Design as an artifact: Design-science research must produce a viable artifact in the form of construct, a model, a method, or an instantiation.

2. Problem relevance: The objective of design-science research is to develop technology-based solutions to important and relevant business problems.

3. Design evaluation: The utility, quality, and efficacy of a design artifact must be rigorously demonstrated via well-executed evaluation methods.

4. Research contributions: Effective design-science research must provide clear and verifiable contributions in the areas of the design artifact, design foundations, and/or design methodologies.

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5. Research rigor: Design-science research relies upon the application of rigorous methods in both the construction and the evaluation of the design artifact.

6. Design as a search process: The search of an effective artifact requires utilizing available means to reach desired end while satisfying laws in the problem environment.

7. Communication of research: Design-science research must be presented effectively both to technology-oriented as well as management-oriented audiences.

In the design research phase of this study, the aim was to build a model for an Internet course for MS patients and for the virtual community that developed during the course in a way that the technical environment would not change when the course ends. This part of the study covers the definition phase of an artifact – the Internet course as a whole with its elements: the people and the tool – and it finishes without implementing or testing the solution. In the ex-ante evaluation phase, different ways of problem solution will be compared.

3.1.3 Summary of the methods

As a summary of the methods used, I will recap their most essential points. In my thesis, the case study was from the very beginning an obvious method, as the focus of the study has been on a contemporary phenomenon within real-life context –
Internet rehabilitation courses for people with MS. Design research method and the further methodological issues in each phase of the case studies were decided upon during the study process.

The case study was applied in those study phases where the course participants' actions were depicted. All case study phases in my thesis are categorized as descriptive (Yin, 2003) and Type I: Theory for Analyzing and Describing (Gregor; 2002, 2006). I tested in the case studies Preece's (2000) virtual community theory and Resnick's (2002) socio-technical capital theory in real life. After publishing all papers, I complemented my theoretical analysis by using Iriberri and Leroy's (2009) theory of online communities' success factors, which is described in Chapter 7.

Design research was applied in one phase of my study, which was after the end of the courses, when the technical discussion environment was closed but the course participants wished to continue interaction on the Internet. In the design research phase, I suggested a model of an Internet course and considered the topic from the perspective of the discussion tool. I used the design research method described by March and Smith (1995), van Aken (2004), and Hevner et al. (2004) in designing the model of an Internet course, which according to Gregor's (2002, 2006) categorization can be seen as Type V: Theory for Design and Action.

3.2   Validity and reliability in case studies

The evaluation of validity and reliability of this investigation has been a challenging task. Yet, the discussion of rigor is important for assuring the adequate scientific quality also in this study. I will concentrate on rigor in theory testing case studies and design research, and I will present the criteria I will use in my self-evaluation of rigor later in Chapter 6 of this summary.

3.2.1 About validity

Järvinen (2004) argues that the validity regards the extent to which an observation measures what it purports to measure. Validity means that a theory, model, or concept accurately describes reality. Miles and Huberman (1994) wrote about the validity of a case research and Hevner et al. (2004) wrote about the validity of design research.

Miles and Huberman (1994) suggest a list of validity checks. They list many questions concerning internal validity, of which I have picked three:

1. Are the presented data well linked to the categories of prior or emerging theory? Do the measures reflect the constructs in play?

2. Was negative evidence sought for?

3. Were the conclusions considered to be accurate by original informants? If not, is there a coherent explanation for this?

I picked the next five questions to measure external validity:

1. Are the characteristics of the original sample of persons, settings, processes etc. fully described enough to permit adequate comparisons with other samples?

2. Does the report examine possible threats to generalizability? Have limiting effects of sample selection, the setting, history and constructs used been discussed?

3. Are the findings congruent with, connected to, or confirmatory of prior theory?

4. Are the processes and outcomes described in conclusions generic enough to be applicable in other settings, even ones of a different nature?

5. Have narrative sequences (plots, histories, stories) been preserved unobscured?

Hevner et al. (2004) gave seven guidelines for design research, of which I use here the one concerning rigor in design research. According to Hevner et al., rigor addresses the way in which the research is conducted. Design-science research requires the application of rigorous methods in both the construction and evaluation of the designed artifact, and rigor must be assessed with respect to the applicability and generalizability of the artifact.

Lee (1989) described some problems in rigor and in the relevance of a single case study. According to him, the problems concern statistical generalizability, the difficulties to make logical deductions because of the often qualitative data, and the difficulties in replicating and finding the same combination of people, groups, social constructions, environments etc. and verifying the foundations. Lee said about falsifiability that the case study with any predictions through which the theory of interest could be proven wrong, could be enough for falsifying the theory.

3.2.2 About reliability

According to Gummesson (2000) and Järvinen (2004), reliability regards the extent to which observations by multiple researchers studying the same phenomenon with similar purposes will yield approximately the same results. In considering reliability, Miles and Huberman (1994) gave a list of reliability checks from many perspectives, and I will use their list in my self-evaluation of rigor.

I picked the following points of Miles and Huberman's list of queries for reliability, dependability and auditability:

1. Are the research questions clear, and are the features of the study design congruent with them?
2. Are the researcher's role and status within the site explicitly described?
3. Were any forms of peer or collegial review in place?

4 THE STUDY

In this chapter, I describe the process of how the whole investigation was executed: the cases, the data collecting process, and the analysis of the data. The description covers the cycle of the whole study, and the phases of the investigation form an entirety. A detailed description of each phase can be found in Chapter 5, where all the papers are summarized.

4.1 The cases

This study concerns two Internet-based rehabilitation courses arranged by the Finnish MS Society for people recently diagnosed with MS. Both courses had the same pattern, objectives, environment and the same processes. The people, their geographical environment, and the schedules were different. The courses were titled "Power and Support from the Net" and they were held:

- The first course from 21 November 2005 to 25 August 2006
- The second course from 6 October 2006 to 20 April 2007.

The participants of the courses were recruited via the Finnish neurological journal Avain [the Key], via the website of the Finnish MS Society, and via a mass e-mail to the society members living in the target areas of Finland. Admission criteria for the participants were following:

- The people should be interested in communication via the Internet
- Both sexes should be represented
- Motivation to obtain and to share information was required
- Access to the Internet at home/at work was required
- No age limit was set.

The candidates signed up to the courses and the experts from the Finnish MS Society selected the participants. The first course was especially directed to people who live in Northern Finland or in the Finnish Lakeland, which are both sparsely

inhabited areas where the people suffering from MS very seldom can have contact with others in a similar situation. The second course was directed to people who live in the Helsinki metropolitan area and in the surrounding region of Uusimaa, which are both densely populated areas and thus converse to the target group of the first course. People on the second course were able to have more contacts with other MS diseased in their everyday life.

Two rehabilitation professionals from the Finnish MS Society acted as course tutors and were active facilitators in the course conversations as well. The tutors were the same on both courses – a male and a female – but the courses themselves did not communicate with each other. The courses started with kick-off meetings where the participants and the tutors got to know each other, set the objectives and themes for the course, fixed the internal rules, and learned how to use the Internet and the Nettineuvola discussion forum. The durations of the courses were also set in these meetings. The objectives of both courses were identical: to offer a discussion forum to the participants and to help them to adapt to the new situation in their lives. The course offered to the participants:

- Opportunities to exchange and share experiences, thoughts and feelings about living with MS,
- Opportunities to find answers to questions concerning MS from other people in a similar situation,
- Opportunities to obtain information about MS, its cure and rehabilitation..

The courses were arranged on the Internet as closed discussion groups, where the participants had access with a personal username and password. The program used on the courses was Nettineuvola by Mindcom Oy (Mindcom, 2009). Nettineuvola is a web-based interactive welfare clinic and learning environment, which was adapted to suit for the needs of the MS Society. The participants created the content in the discussions in textual form with neither attachments nor pictures. The discussions consisted of themes and each theme consisted of messages, which in turn consisted of questions, opinions, or advice. The replies to the messages and the replies to the replies constituted the discussion hierarchy. The interaction occurred asynchronously regardless of time and space.

The courses ended in closing sessions where the participants and the tutors met face-to-face. The closing meeting was important for sharing experiences but also

for the participants to close the course and to face each other after long and even intimate discussions.

I prepared my study with the MS Society experts who were planning the course and acted as course tutors. The experts approved the research questions, which I had prepared, and they accepted the way in which the study was to be performed. I as a researcher did not have access to the contents of discussions, which was the condition set by the course participants taking part in the research.

4.2 The schedule of the study

The schedule of the study was set according to the courses (Figure 2). The study started from the Internet Course 1 "Power and Support from the Net", which was the first investigation focus. Course 1 was investigated as a longitudinal study starting from the expectations in the beginning and ending with the experiences and feelings at the end situation (1). The study continued with Course 2 and when it ended, a cross-case study about the expectations and their fulfillments was executed (2).
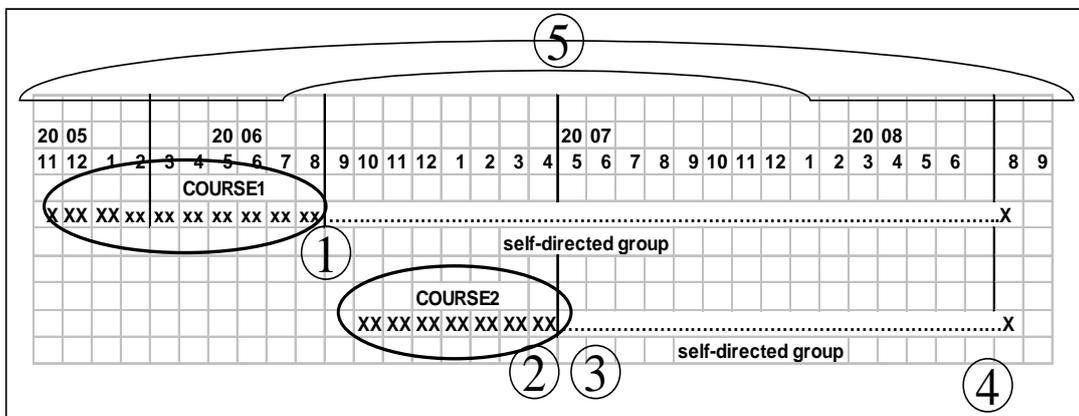
Figure 2. The schedule of the study

Both courses ended with closing sessions, but the participants wished to continue the interaction in self-directed communities without tutors. As the possibility of using the Nettineuvola discussion forum ended with the courses, the tool had to be changed to group e-mail. The third phase of the investigation concerns this change (3), and there the focus was the model of an Internet course and the problems caused by the change in the technical environment. As the time passed, the communities

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had a possibility to continue the interaction by e-mail. After a relatively long time –
one year after the second course and two years after the first course – a study was
conducted on whether the communities were still alive (4). Hence the whole study
process lasted from the start of the first course in the autumn 2005 to the late
moment in the summer 2008, which constitutes the whole life cycle of this research
(5).

Table 3. The phases and methods of the study

Phase and time	Method	Explanation	Papers
Phase (1), after the course 1, autumn 2006	Case study	The first case is a single, longitudinal case, lasting from 21st November 2005 to 25th August 2006. Gregor (2002, 2006) has categorized the theory as Type I: Theory for Analyzing and Describing.	Paper 1
Phase (2), after the course 2, spring 2007	Case study	In the second case the study compares the similarities and differences between on course 1 and course 2. The study is also a theory testing one where I used Järvinen's (2010) new taxonomy for developing and tested new theories in testing Preece's theory and the results from the first phase of my study. Gregor (2002, 2006) has categorized the theory as Type I: Theory for Analyzing and Describing.	Paper 2
Phase (3), after both courses, spring 2007	Design research	In the third phase I applied design science method described by March and Smith (1995), van Aken (2004), and Hevner et al. (2004) in designing the model of an Internet course. Gregor (2002, 2006) has categorized the theory as Type V: Theory for Design and Action.	Paper 3
Phase (4), course 1 and course 2, summer 2008	Case study	The fourth case is a longitudinal one concerning both courses and lasting from November 2005 to August 2008. The study phase is theory testing, and it tests Resnick's (2002) socio-technical capital theory in real life. Gregor (2002, 2006) has categorized the theory as Type I: Theory for Analyzing and Describing.	Paper 4
Phase (5)	Summary	Phase 5 is a thesis that collects all the earlier phases into one compilation. Iriberri and Leroy's (2009) theory of online community life cycle and success factors supplemented the results of papers published.	The dissertation

The phases of my study and the methods used are summarized in Table 3. After each phase, a paper was written for publishing either in a scientific conference or in a journal. The table includes also Iriberri and Leroy's (2009) theory, which was added to this thesis in the summary phase.

4.3 Data collection

The data collection followed the schedule of the research and it was performed in the following steps (Table 4): three times during the first course, once at the end of the second course, and once a lengthy time after the courses had ended. The data collection was made by questionnaires to the course participants and by interviews with the participants as well as with the tutors. The course participants were asked an approval to answer the questionnaires, to take part in the interviews, and the permission to record the interviews. The participants were guaranteed that their identities would remain anonymous.

Processing the answers of the questionnaires was identical in each phase of the study. All questionnaires were printed on paper and mailed to a tutor, who delivered them to the participants. The questions were mostly unstructured, which brought a qualitative perspective to the study, but some questions about the facts as well as about the opinions were structured with 5-degree scaling from "very much" to "very little" or from "easy" to "difficult" making a quantitative perspective possible. The participants posted their answers directly to me or via the tutor to me.

All the questions and answers were organized according to Preece's (2000) categories: *purpose, people, policies, and computer*. The course participants were coded by course (Course 1 and Course 2) and by participant from A1…An. Each answer was identified according to a code referring to the answerer. Answers to the unstructured questions were transcribed on Microsoft Word and answers to structured questions on Microsoft Excel. After that, the answers were rearranged according to each question. Because of the small number of participants, all the answers could be taken into account.

Table 4. The data collection steps

Activity	Time	Questions	Target group
Invitation letter	Nov 2005	Appendix 1a	Members of MS Society
Phase1, Course 1			
Start of the course 1	**21 Nov 2005**		
Questionnaire 1	November 2005	Appendix 1b	Participants
End of the tutored phase	**28 Feb 2006**		
Questionnaire 2	February 2006	Appendix 1c	Participants
Interview 1	March 2006	Appendix 1d	Tutors
End of the course 1	**28 Aug 2006**		
Questionnaire 3	August 2006	Appendix 1e	Participants
Interview 2	September 2006	Appendix 1f	Participants
Interview 3	November 2006	Appendix 1g	Tutors
Phase2, Course 2			
Start of the course 2	**6 Oct 2006**		
End of the course 2	**20 Apr 2007**	**.**	**-**
Questionnaire 4	April 2007	Appendix 2a	Participants
Interview 4	May 2007	Appendix 2b	Participants
Interview 5	June 2007	Appendix 2c	Tutors
Phase 4 Course 1 and Course 2			
One or two years after the courses	**Summer 2008**		
Questionnaire 5	June 2008	Appendix 3a	Participants
Interview 6	July 2008	Appendix 3b	Participants

Processing the answers to the interview questions was identical in each phase of the study. Because of the distance between me and the course participants was long, the only way to perform the interviews was by telephone. In order to conduct the interviews, I needed the participants' telephone numbers and e-mail addresses to arrange the schedule of the interviews. The main topics were sent to the participants by e-mail to give them a possibility to prepare for the interview.

The interview questions were open and the interview situations were informal. The identities of the course participants were kept anonymous in the interviews as

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well. The tutors' were interviewed partly face-to-face as a team and partly separate by telephone. All the interviews were recorded according to the permission granted by the interviewees. After recording, every interview was transcribed on Microsoft Word. Again, the answers of the interviews were rearranged according to each question.

4.4 Data analysis

The number of the answers in the questionnaires as well as in the interviews was small, because of the small number of the informants. Hence it was possible to examine and analyze the data completely. All the transcribed answers from the questionnaires as well as from the interviews in study phases 1-2 were recorded according to the questions either on MS Word or on MS Excel. The questions and the answers were categorized according to Preece's (2000) categories of virtual communities: people, purpose, policies, and computer. The saved data was organized by the course, the category, the question and the answers to a question.

The analysis of the answers was executed according to Yin's (2003) and Eisenhardts's (1989) descriptions of analyzing the case studies. The basic goal of qualitative data analysis is the understanding, which means the search for coherence and order. I used within-case and cross-case analysis methods in this study. The analysis started as within-case analysis by identifying the essential findings for each question from both courses separately. The essential categories concerning, e.g. the benefits from the courses, were identified by combining similar expressions such as "trust" or "empathy", or synonyms such as "accept" and "allow". Within-case analysis is seen as a key step of an analysis. It allows unique patterns of each case to emerge before investigators push to generalize patterns across the cases (Eisenhardt, 1989). In the cases at hand, it was difficult to generalize anything because of their small size, but the analysis can give suggestive results.

After the within-case analysis, the analysis continued as a cross-case analysis. One tactic of cross-case analysis is to select pairs of cases and list the similarities and differences between the cases, as was done in this investigation. The idea behind this tactic is to force investigators to go beyond initial impressions through the use of structured and diverse lenses on the data. These tactics improve the

likelihood of accurate and reliable view, and enhance the probability of the investigator capturing the novel findings, which may exist in the data (Eisenhardt, 1989). This tactic was suitable for this study because of the objective to find some essential features in the cases, which would have similar scope, or to recognize the differences between the courses.

5 PRESENTATION OF THE RESEARCH PAPERS

In this chapter, I will present my four published papers in the order of the study process and the publication dates of the papers. The description of each paper contains the research problem of the paper, the research method used, and the results that I emphasize in the paper. The first paper describes the sociability on one Internet course (Course 1) in a longitudinal theory-testing case study. The second paper is a two case study that compares the two Internet courses (Course 1 and Course 2) describing the similarities and differences between them. The third paper changes the view to design research and presents a suggestion for a model of an Internet course. The fourth paper is again a case study that looks at the virtual communities created by the two courses from a longer time perspective and from a socio-technical capital view. All the papers together form a coherent story of the courses during a three-year period.

5.1 Research Paper 1: Heikkinen, M., Power and support from the net – usability and sociability on an Internet-based rehabilitation course for people with multiple sclerosis. International Journal of Web Based Communities, Vol.5, No. 1, 2009, pp. 83-104.

5.1.1 Research problem

The main research problem of the whole investigation was to discover the feasibility of the Internet for rehabilitation courses for people with MS. The first paper focuses on the concept of a virtual community and the sociability within the community according to Preece (2000), and the problem was formulated further in these questions:

- *Did the participants of the course create a virtual community?*
- *Did my investigation apply to Preece's criteria on virtual community?*
- *How is the sociability on the course expressed?*

In order to find out whether the course would have the characteristics of a virtual community, I developed more detailed questions from the research problems (Appendix 1) which were then organized according to Preece's theory of virtual communities: the purpose, the people, the policies of the community, and the computer matters. The questions in the purpose category concerned the participants' expectations of the course, and the help they expected to get and actually got about the MS itself. The questions in the people category concerned the roles the participants expected to have or felt they had during the course, the ways of interaction and the sense of belonging to the group. The questions in the policies category concerned the tone of the interaction and the feelings between anonymous / known people in the community. The questions in the computer category concerned the experiences of computer use and the Internet in general, and the experiences of using Nettineuvola as the course tool.

5.1.2 Research method

The selected research strategy in this phase was a case study (Eisenhardt, 1989; Lee, 1989; Klein and Myers, 1999; Yin, 2003; Järvinen, 2004; Eisenhardt and Graebner, 2007). Although there are a lot of studies on virtual communities in general, limiting this study on a small closed group and rehabilitation of MS focuses it on an under-researched area. In the first phase of my study, I investigated one course in three steps, which makes the method of the first study phase a single longitudinal case study. The research is mainly qualitative but it has some quantitative aspects as well.

The research started by exploring the literature concerning the theories of virtual communities (Rheingold, 1995; Whittaker et al., 1997; Lazar and Preece, 1998; Preece, 2000; Schubert and Ginsburg, 2000; Wellman, 2001; Whitworth and de Moor, 2003). There is extensive literature on virtual communities, but I limited the focus on the health care communities and social perspective. Preece's (2000) theory

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of virtual communities turned out to be the most suitable one for analyzing and classifying the virtual communities because of its comprehensive and structured construction.

When thinking about the start phase of my investigation, I felt that it would be clearer and more reliable to base my study on an existent theory trying to test it in a real case than to start from scratch. According to Järvinen (2004), a theory-testing research tries to answer the question whether a particular theory, model or framework describes a certain part of the reality well. In my case, I tried to show that Preece's theory could be applied in describing the studied Internet course. I investigated whether the course participants' opinions and feelings were in accordance with Preece's four virtual community components.

5.1.3 Research results

Ten people had signed up on the Course1 but only eight were present in the kick-off meeting. The ages of the participants varied from 26 to 55 years, and there was only one male participant. Two people dropped out during the course, hence six were left at the end of the course. The number of participants is small for making generalizations, but some descriptive perceptions of this particular case can be done.

In considering the first research question (*Did the participants create a virtual community?*), I can conclude that the course participants in this case comprised a group with common interests, shared goals, and activities. An overwhelming expectation of the course was *"Peer support",* which strongly confirms common interests and shared goals. People constituted a group where individuals cooperated to share and to satisfy each other's needs (Rheingold, 1995; Preece, 2000) and the groups comprised socially self-sustaining groups in a computer-mediated space (Schubert and Ginsburg, 2000; Whitworth and de Moor, 2003). According to these definitions, I could give a positive answer to the first research question.

In considering the second research question (*Did my investigation apply to Preece's criteria?*), I will explain the results by following Preece's four components of virtual communities: purpose, people, policies, and computer. The original *purposes* of the course were the opportunities to exchange and share experiences, thoughts and feelings about living with MS, the opportunities to find answers to

questions concerning MS from other people in a similar situation, and the opportunities to obtain information about MS, its cure and rehabilitation. The course participants and tutors did accept these purposes. The title of the course – "Power and Support from the Net" – described well the purpose of the course. Concerning the *people* category, the community members communicated intensively on the net. They had different roles: pre-defined like tutors and participants; and ad-hoc roles like active questioners or commentators, readers, etc. The participants felt they obtained "*togetherness, encouragement, advice, peer support, information, nice friends, empathy, and understanding*" from the course, and that they could create an environment of deep trust among themselves. *Policies* and ways of discussion showed that the participants relied on the security level of the course. The community membership was limited to the known persons who used user-ids and passwords. The discussion policies were fixed in the kick-off meeting when the participants met each other. The tutors also could have moderated the discussion if needed.

According to Preece (2000), a virtual community needs good usability to support the sociability of the community. In my case, the technical infrastructure and the communication tool used, Nettineuvola – both components of the *computer* category – worked well and offered a functioning technical environment for the discussions and the sociability of the community.

As for the main research question about the feasibility of the Internet for rehabilitation courses, I will present some detailed results. According to the tutors, the activity on Course 1 was high in the first three months, being in total 697 written messages, and on average 100 messages/participant and 0,8 messages/participant/day. The activity decreased when the tutors withdrew to the background, being during the last six months in total 454 messages, and on average 76 messages/participant and 0,4 messages/participant/day. The tutors were surprised about the high activity and the spontaneous and long discussions, as well as about the small need for tutors' intervention in the discussions.

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5.2 Research Paper 2: Heikkinen, M., Similarities and differences of two web courses for people with multiple sclerosis. Proceedings of IADIS WBC 2008, 24. - 26.7.2008, Amsterdam, Netherlands, pp. 169-173.

5.2.1 Research problem

The second paper was written after the second "Power and Support from the Net" course. The results of the first course were known when the second phase of the investigation was executed, and in this paper I compare the two courses. The main research problem of this phase can be divided into three sub-problems:

1) Which were the similarities or differences expressed between the two courses?

2) Why did the differences exist and what were their effects on the community?

3) Can we widen or enrich the results of the first phase and how?

To assure the comparability between the two courses and the two investigation phases, the questions of the questionnaires as well as the interviews in this phase were based on Preece's (2000) model of virtual communities.

5.2.2 Research method

The second phase of my investigation continued as a case study, but it had two cases under exploration. The second course had started without my involvement, due to which the start and end study activities had to be merged, and the questionnaire and the interviews (Appendix 2) were conducted only once – at the end of the course. The questionnaire covered the basic information of the participants, their original expectations of the course, realization of the expectations, and the wishes for the future. The questions followed the same structure as on the first course, outlined according to Preece's (2000) categories, and were comparable with the questions in first phase.

In this phase, I have tried to confirm or contradict the results of the first phase by widening the study to another case and then comparing the cases. In this phase, I tested Preece's categories complemented with the results from the first phase and applied to Järvinen's (2010) new taxonomy of developing and testing theories.

The analysis of the data followed Yin's (2003), and Eisenhardt's (1989) within-case and cross-case analysis. Within-case analysis usually copes with large amount of data, and typically it involves detailed case study write-ups for each site, where the write-ups are often simply pure descriptions. My case copes with very small amount of data and I analyzed both cases as a whole. In the cross-case analysis, I identified the similarities and differences between the courses.

5.2.3 Research results

One essential result in the second study phase was, that "similar" courses don't necessarily mean identical. Although the technical environment – the Nettineuvola discussion forum and the closed discussion group on the Internet – were similar and both courses seemed to have many common features, there were some remarkable differences between the courses and the virtual communities they constituted. I will first describe the similarities and the differences and analyze the reasons for them.

Similarities between the courses

There were similarities on both courses in several issues:
- The number of selected participants was 10 on both courses
- Both courses had wide age distribution (under 30 to over than 55 years) and a female majority, and neither of the aforementioned factors had no major influence on the activities of the courses
- The atmosphere on both courses was very positive and trustful
- Both courses had a high discussion activity in the beginning of the course, which decreased towards the end. The presence of the tutors activated the communities and their absence seemed to cause some deactivation.
- Peer support was considered the most important benefit on both courses
- Both courses emphasized the importance of the face-to-face opening meeting and knowing other course participants personally. The participants did not

see the discussing in anonymous groups as trustful as in a closed group with people they had met in person.

- Both courses regarded meetings at the end of the courses important to strengthen the trust and to face each other after the open and sensitive discussions.
- The participants were "*the best experts in the cure of MS*". However, the tutors as experts were important in supplementing the information that could be "*correct but in some cases inadequate*".

Differences between the courses and reasons for them

In spite of the similar organization and scope of the courses, there were remarkable differences between them. I separated the differences in environmental factors from the differences caused by the behavior and experiences of the participants.

External or environmental factors different between the courses were:
- The durations and activity levels of the courses were different
- The geographical environments of the participants were different.

Differences caused by the experiences and behavior of the participants were:
- The first course was more active than the second one: on the first course there were 0,8 messages/participant/day and on the second course 0,5 messages/participant/day. The high level of the discussion activity on the first course might come from the strong commitment, sense of togetherness, and the high level of support among the group.
- The styles of writing were different. According to the tutors the discussions on the first course were "*long and considerate, supportive and understanding*", and on the second course they were much shorter, and sometimes "*determined, even opinionated*". On the first course the participants had less experience of other Internet discussion groups, which might to be one reason for the different writing styles. Also the different living environments, north – south, may cause differences in communication styles.

- The participants' diverse health statuses caused differences between the two courses. On the second course, those who were healthier than other, felt they were outsiders and did not take part in conversations as much as the others with more severe symptoms of MS. This did not happen on the first course, because of either more similar health statuses or because of the lack of reporting on it.

- The participants on the second course were more active in commenting the Nettineuvola tool, and even giving a list of propositions for improving it. Possibly the computer experience that some participants on the second course had, made it easier for them to come up with suggestions and notice the problems.

Though the participants on both courses thought the courses were important and useful, some obvious differences between the courses could be detected after the courses. The most important dissimilarity was, that the first course group continued interaction after the actual course, but the second group ended the mutual interaction totally – only some one-to-one e-mails were sent.

5.3 Research Paper 3:Heikkinen, M., A suggestion for a model to an Internet-based rehabilitation course for MS diseased. Proceedings of WIS 2008, Well-being in the Information Society, 19. -21.8.2008, Finland, Turku

5.3.1 Research problem

I executed the third phase of my investigation after the end of the second course, and it considers the ending situations of both courses. The end of the courses created a breaking point in the communities, when the change in the technical environment caused a threat to the existence of the communities. The research questions in this phase are following:

1. *How could we improve the technical solution of the courses to assure the opportunity to continue the existence of a living virtual community?*

2. *What kind of possibilities would there be to continue the communication fluently after the courses?*

3. *How can we introduce a model for an Internet course?*

The point of view of the research changed from virtual communities' social action to the technical questions, and the focal point in this phase was the software the virtual community used.

5.3.2 Research method

I changed the methodological point of view of the investigation from a theory-testing case study to a design research. The problem with the technical environment after the end of a course needs solving: how to guarantee seamless continuation of the virtual community created during the course after the course as well? It is a question about improving the technical solution, which makes this phase a design research (Järvinen (2004), van Aken (2004).

Hevner et al. (2004) recommend in their design research guidelines, that a researcher should design an artifact, which in my study is the model of an Internet course. The problem to solve was the situation with the discussion tool at the end of a course, when the Nettineuvola forum was closed but the course participants wished to continue their interaction. The initial stage (March and Smith, 1995) is the model of an Internet course as it was during the actual course time. I made a suggestion for a new model for an Internet course to solve the problem with the communication break created by the tool change after the course. The goal stage was the new model for an Internet course where the discussion tool for the community could stay the same during the course and in a self-managed community after the course.

The design process covered the definitions of the requirements phase leaving out the implementing and testing phases of the solution. The further execution of the phases would have required collaboration with the MS Society, which was not possible during this investigation time. The evaluation of the definition phase concerns considering the alternative solutions and their effects on sociability and usability in the community's action.

5.3.3 Research results

The results of the third paper were collected in phases: First I presented the initial life-cycle model of an Internet course (Figure 3), secondly I summarized the pros and cons of the courses, and finally I suggested the new life-cycle model including alternative solutions for the tool.

The life cycle model

Because a model for the initial life cycle of an Internet course did not exist, I considered it important to describe the situation as it was during the investigation. The original course contains the phases (1.) - (6.). Phase (7.) consists of the self-managed period after the course.

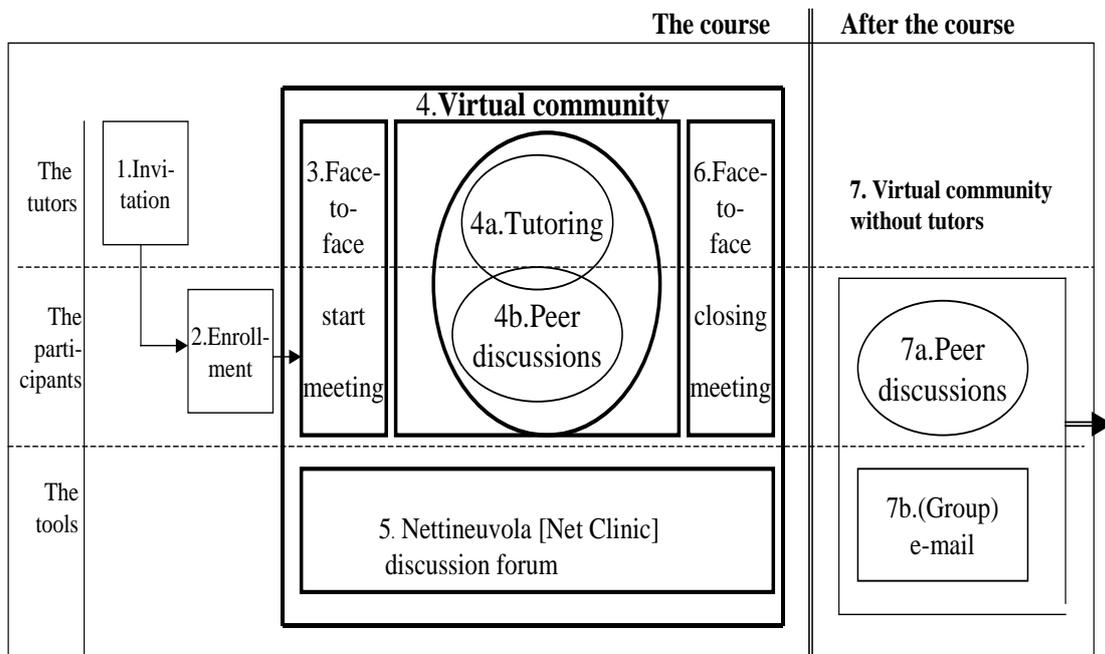Figure 3. The life cycle model of an Internet course

Pros and cons of the Internet courses

The pros and cons of the courses (Table 5) were analyzed as an addition to the earlier study phases, and their analysis was the base for weighing the solution to the problem of the break in the interaction. The experiences from the courses were mostly positive but there were some things that were considered weaknesses.

Table 5. Summary of the results according to Preece's (2000) categories

Category	*Pros (+)*	*Cons (-)*
Purpose	+Peer support +Getting information +Getting/giving help	-Lack of physical rehabilitation -A more course-like course with more structured and teaching content was expected
People	+Knowing the participants beforehand +Togetherness, encouragement, advice, support, information, empathy, understanding +All felt to be members of a group more than individuals +High activity +Tutors were important +Communication in the Internet was easier than on face-to-face courses	-Lack of face-to-face contacts -Easy to stay passive and out of conversations when nobody was pushing for active participation - Difficulties in finding right words when expressing oneself
Policies	+Trust and security +Polite and emphatic discussions +No discipline needed +Humor	-Lack of body language could cause misunderstandings
Computer	+Infrastructure worked well +Nettineuvola was easy to learn and use +No help was needed	- Some bugs and inconveniences were found in Nettineuvola tool

Suggestion for a new life cycle model

The focus of creating the new life cycle model was the discussion tool: *What kind of possibilities would there be to continue the communication fluently after the courses*? There might be four alternative possibilities that offer a method for a fluent continuation of the interaction (Table 6):

Table 6. The alternatives of the discussion tools on the course and after the course

	Tool on the course	Tool after the course	Pros after the course	Cons after the course
1.	Nettineuvola	Group e-mail	+ Possibilities for attachments + No special arrangements	- Course history is not available nor saved
2.	Nettineuvola	Nettineuvola	+ Course history available + Familiar tool	- Costs - Management after the course
3.	Nettineuvola	New free tool	+ Free + Advanced possibilities	- New tool to learn - Management after the course - Challenges in security and privacy, and in deleting the community after its existence
4.	New free tool	New free tool	+ Free + Advanced possibilities	- Management after the course -Challenges in security and privacy and in deleting the community after its existence

    1. The first alternative is to maintain the situation as was in the real life cases: to use Nettineuvola discussion forum during the course time, to accept the break at the course end, and to continue the interaction by group e-mail. It does not need new arrangements, and if the weaknesses of this solution are acceptable, it is a working and easy solution. In practice, this would be the easiest way to continue.

    2. The second alternative is to maintain the same Nettineuvola tool as during the course through the whole life cycle of the community –, during the course time and after the course. Yet, this may be difficult, because the contract with the supplier of Nettineuvola ended with the courses, and the Finnish MS Society was not responsible for its use anymore. New arrangements should be made and they would require financial commitment concerning the tool and the technical implementation of the environment.

    3. The third alternative is to use Nettineuvola on the course but change the tool after the course to a totally new, free-of-charge tool, which should be created and managed by the virtual community itself. There are lots of free-of-charge tools on the Internet, but selecting an adequate one would be a challenging task. Web 2.0

has brought new possibilities such as GoogleGroups, Facebook or Twitter for creating new closed discussion groups. Problems can still occur with who would be responsible for selecting the tool and installing and managing the technical environment during the group's lifetime. This phase would need an own project to define the actual needs, the implementation environment and the management organization, but that project is out of the scope of this investigation.

4. The fourth alternative is to change the discussion tool in the very beginning of the course to a free-of-charge tool that would remain same after the course and during the whole lifetime of the community. Here it might come to question to use the same tools as in the previous alternative: GoogleGroups, Facebook, Twitter etc. The pros and cons of this alternative are similar as the previous alternative. One great challenge in using free tools concerns the situation when the community ceases to exist. It should have to be possible to delete the discussion files when the community is no longer active and the possibilities of deletion need further examination. Assuring the data security and privacy must also be taken into account.

The further evaluation of these alternatives and the actual development project would need negotiations with the Finnish MS Society, which was not possible during this study process.

5.4 Research Paper 4: Heikkinen, M., Socio-technical capital among two virtual communities for people with multiple sclerosis. Proceedings of IADIS ICT, Society, and Human Beings, 21.-23.6.2009, Algarve, Portugal, pp. 155-162 .

5.4.1 Research problem

The fourth phase focuses on studying the existence of the two communities created by the "Power and Support from the Net" courses. This phase was executed two years after the first course and one and half year after the second course, when the community members intended to interact via group e-mail.

The research question of this paper was: *Are the earlier studied virtual communities still alive and why or why not*? This sub-question emerged mainly from a practical point of view.

The paper concentrates on socio-technical capital in a virtual community, and in this phase I studied the existence and the development of social capital in a virtual community. Social capital originates from the relations between people (Coleman, 1988), and the relations connected by computers can create socio-technical capital (Resnick, 2002). The scientific research problem can thus be formulated: *How can socio-technical capital be developed in a small and closed virtual community, and what are the motivators in the development*?

5.4.2 Research method

The research strategy in the fourth phase was again a theory-testing case study, but now I applied the theory of social and socio-technological capital. This phase was a follow-up to the two earlier case studies of the two Internet courses. I performed it one or two years after the courses had ended, concentrating on the communities' existence during their self-directed period. Thereby, it was a longitudinal study.

Resnick (2002) described the concept of socio-technical capital in referring to productive cooperation between social relations and ICT. He gave a useful theory for outlining the concept viewing socio-technical capital from the technical point of view. He listed the opportunities and the pitfalls of socio-technical capital and defined seven forms of socio-technical capital, which enable activities or kinds of interaction (Figure 4). I applied Resnick's forms of social capital in this study to investigate the instantiation of socio-technical capital in the communities studied.
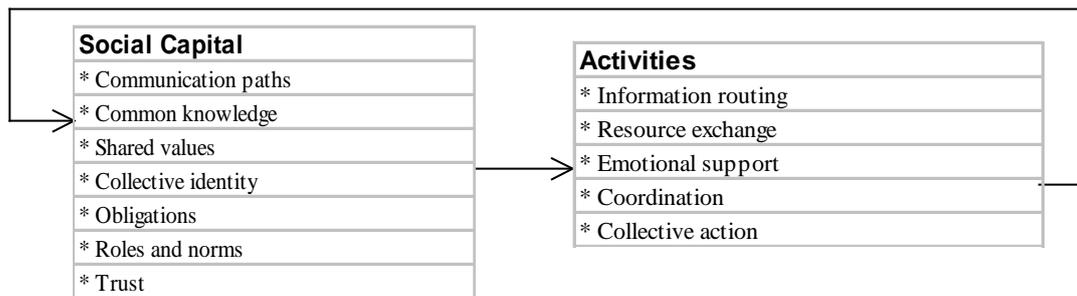
Social Capital		Activities	
* Communication paths		* Information routing	
* Common knowledge		* Resource exchange	
* Shared values		* Emotional support	
* Collective identity		* Coordination	
* Obligations		* Collective action	
* Roles and norms			
* Trust			

Figure 4. The forms of social capital and the kinds of interaction they enable (Resnick, 2002)

5.4.3 Research results

The results of this phase were discussed according to Resnick's (2002) socio-technical capital theory. In addition, I analyzed the course activity as the indicator of the amount of socio-technical capital and according to the effects of the technology.

The activity was a significant indicator in measuring the amount and the degree of socio-technical capital. In this study, when the tutors withdrew from their active facilitator role, the activity decreased. This could be noticed already on Course 1 during the course time, but it was especially noticeable after the end of the courses, particularly when the Course 2 stopped its group interaction completely. The activity on the first course also decreased clearly during the two years from every-day communication to once-a-week communication. Thus, the decrease of socio-technical capital could be noticed clearly.

Communication paths were born in this investigation, when every member of the community could communicate with all the other members and in doing so created socio-technical capital among the community. Some people were even stimulated to contact with their peers outside the course, adding to their communication possibilities and socio-technical capital.

The shared community values were accepted in the opening meeting in order to achieve good cooperation, and those values applied during the course as well as afterwards. Shared knowledge appeared in this study in exchanging information and support among the community members. During the course, the information was stored in a shared database and it comprised of relevant information concerning

MS and rehabilitation. After the course, the data was stored in private e-mail files and its content was more informal.

Collective identity, the community spirit and the sense of belonging to a community were created in the kick-off meetings. The collective identity was high on Course 1, even after the actual course, but it decreased over time. On Course 2, the collective identity varied during the course, and totally dispersed with the end of the course. There were no special obligations on the courses, and the participation was voluntary. Instead of the obligations, I would speak more about the participants' commitment to the course, which substantially affected the existence and activity of the course. The lack of commitment was clearly seen, when the interaction on the second course stopped after the official course.

Roles and norms were partly predetermined and partly spontaneous. The tutors had many roles being activators, discussion starters, experts and outsiders with a "matter-of-fact-policy", not taking part in a personal way like the participants did. The roles of the participants, such as manager, discussion starter, active poster, commentator, or reader were created ad-hoc during the courses and according to the behavior of the participants. The same person could appear in many roles during the course, but nobody took the role of a leader or an activator after the course.

Trust emerged as the most important feature of the socio-technical capital in the two communities studied. The trust existed from the very beginning and it was growing all the time during the course, and there were no signs of its decrease even during the self-directed time. The personal acquaintance of the course participants was emphasized in creating the atmosphere of deep trust.

Technology effects had a central role in creating the socio-technological capital in this investigation. An asynchronous Internet-based discussion forum Nettineuvola gave the possibility to write texts independently of place and time, which was considered a good thing. The change from the discussion forum to e-mail had both positive and negative effects. E-mails became more personal and pictures or links could be attached to them, which added to the possibilities of interaction. .

6 SELF-EVALUATION OF RIGOR

As I wrote earlier, the evaluation of the validity and the reliability of this investigation is a challenging task for me. The objects of study – the Internet courses –followed their own schedules, which I had to keep up with as an outsider. This makes the evaluation of the rigor particularly important to assure the scientific quality of the investigation. In this chapter, I describe my self-evaluation concerning the validity and the reliability and the ethics of the thesis.

6.1 Validity of the investigation

I will here concentrate on the validity of my study using Miles and Huberman's (1994) validity evaluation procedures in theory testing case studies from a qualitative research perspective.

Validation queries by Miles and Huberman (1994)
When evaluating the internal validity, I picked the following questions out of Miles and Huberman's validation queries:

1. Are the presented data well linked to the categories of prior or emerging theory? Do the measures reflect the constructs in play? - The data collected follow Preece's (2000) categories of online communities. This applies also to the questionnaires distributed, the interviews questions and to the method of classifying the answers and the results. The results concerning socio-technical capital are categorized as lenses to Resnick's (2002) theory.

2. Was negative evidence sought for? - No negative evidence was sought for.

3. Were the conclusions considered to be accurate by original informants? If not, is there a coherent explanation for this? –The summary of the

answers was presented to the tutors of the courses, and they did not have contradictory opinions to my conclusions. The original informants had no possibility to check the accuracy of the conclusions because of the difficulties of reaching the informants.

When evaluating the external validity. I used the following arguments to reply Miles and Huberman's questions:

1. Are the characteristics of the original sample of persons, settings, processes etc. fully described enough to permit adequate comparisons with other samples? – There was no sample of persons, but the two Internet courses studied were the only MS rehabilitation courses at the study time, and the informants included all the participants of those courses as well as the tutors. I had no possibility to influence the selection of the persons studied.

2. Does the report examine possible threats to generalizability? Have limiting effects of sample selection, the setting, history and constructs used been discussed? – Because of the small target group, about 20 persons, two courses and one disease, the possibilities for statistical generalization in my investigation are limited. Instead of that, Lee and Baskerville (2003) wrote about analytical generalization in academic research; i.e., some concepts used can be generalized. For example, the model of an Internet course, which is a new concept that did not exist earlier, can be used in other context as well.

3. Are the findings congruent with, connected to, or confirmatory of prior theory? – The results are congruent with the earlier theories by Preece (2000) and Resnick (2002), and they support both Preece's theory of virtual communities and Resnick's theory of socio-technical capital.

4. Are the processes and outcomes described in conclusions generic enough to be applicable in other settings, even ones of a different nature? – The study process and the outcomes can be applied in testing Preece's and Resnick's theories with the rehabilitation of other long-term diseases, and thus they are generic enough. Yet, the technical development concerning the available tools is in 2011 has changed from the course

time, which can decrease the applicability and generalizability of the study.

5. Have narrative sequences (plots, histories, stories) been preserved unobscured? - The [from the Finnish language] translated questions are printed in Appendices. The original replies [in Finnish] are saved either as paper copies (the replies of the questionnaires) or as recorded speech files (the interviews). The reply texts and the interviews were transcribed to MS Word- or MS-Excel files, categorized according to the questions, and saved for the present.

Lee (1989) wrote about the difficulties to make logical deductions in case studies because of the often qualitative data, the difficulty of replicating and finding the same combination of people, groups, social constructions, environments and verifying the foundations. Concerning the first argument, I had some quantitative data, the numbers of the discussions that could be used for measuring the discussion activity, comparing the activity between the two courses and measuring the development of socio-technical capital in the cases. The replication problem existed in my investigation, though the targets, the organization, the tutors, the technical environments of the two courses were similar, but the lengths of the courses, the course participants, and the geographical environments were different.

Based on the evaluation arguments presented, I have come to the conclusion that, despite some challenges, the quality of my investigation sufficiently fulfils the demands of validity in a scientific research.

6.2 Reliability of the investigation

Järvinen (2004) argues that reliability regards the extent to which investigative activities by multiple researchers studying the same phenomenon with similar purposes will yield approximately the same results. I will here concentrate on self-evaluation of the reliability in my investigation, and in order to self-evaluate my investigation I will use Miles and Huberman's (1994), queries for reliability, dependability and auditability:

1. Are the research questions clear, and are the features of the study design congruent with them. – The research question about the feasibility of the Internet for MS rehabilitation emerged from practice, and the focus points concern virtual communities categorized by Preece (2000). The question acted as the leading idea through the whole investigation, and the main question was complemented by new sub-questions. All the questions in the questionnaires given to and in the interviews conducted with the participants and the tutors are listed in Appendices.

2. Is the researcher's role and status within the site explicitly described? - I devised the questionnaires distributed to the course participants and interviewed the participants and the tutors, but otherwise I was an outsider who did not take part in the courses themselves. I had no possibility to see the contents of the conversations during the courses.

3. Were any forms of peer of colleague review in place? – Research questions were pre-reviewed by the experts of the Finnish MS Society, by the doctoral student colleagues and by some persons who have MS but no scientific experience. The student colleagues had a possibility to comment my analysis, and the tutors of the rehabilitation courses accepted my conclusions of the results.

I consider the reliability of the investigation sufficient. The investigation has followed practice more than science, but according to the previous arguments, I see the study reliable.

6.3 Rigor in design research phase

Hevner et al. (2004) listed seven guidelines for design research, about which I used the one that concerns research rigor. According to Hevner et al., design research requires the application of rigorous methods in both the construction and the evaluation of the designed artifact, and rigor must be assessed with respect to the applicability and generalizability of the artifact.

In my investigation, the model of an Internet rehabilitation course is an artifact, where a course acts as a starting event of a long-term virtual community for MS

patients. The importance of the model is relevant, because the concept of an Internet course is rather new and there were no existing models for an Internet course. Also, the need to evaluate and change the technical environment emerged during the investigation process, when at the end of the courses the technical discussion environment was shut down but the need to continue the interaction on the Internet persisted.

In my research process, I used March and Smith's (1995) and van Aken's (2004) suggestions for design research and described the model of a course at the initial state and at the proposed goal state. I presented four alternative possibilities for the new technical environments, but it was not possible to implement and test the alternatives in practice. Thus, the solution stays on the level of suggestion and the model might need further design before its implementation is possible. The model suggested can also be adapted on rehabilitation courses for patients of other long-term diseases, and therefore the model can be considered analytically generalizable. From a technological perspective, the new model can work as a starting point for further projects, when the appropriate technical solution for interaction is selected. From the human perspective, and especially from the course participants' and the course organization's point of view, the course as an independent and a limited-time event can in the future act as a trigger for a long-term virtual community, if the technical environment supports the seamless continuation from a course to an independent virtual community.

6.4 Ethical aspects

Because my research concerns patients who have the neurological disease MS, the Finnish MS Society suggested asking a statement from the Ethics Committee of the University of Tampere. At the time of data collection, such a committee did not exist, so I asked the statement from the Ethics Committee of Pirkanmaa Hospital District.

I received an approving statement [ETL-code R04184/12.8.2005] in which the Ethics Committee "*does not see any constraints for carrying out the research*". The directives of the Committee are based on the Declaration of Helsinki (WMA, 2008)". Although the Declaration is addressed primarily to physicians, the WMA

encourages other participants in medical research involving human subjects to adopt these principles, and I have tried to follow the principles in my study.

According to the guidelines, I sent the course participants a patient information letter where I asked them to participate in the investigation and where I explained the objectives of the investigation and the study process. I also asked them to sign a letter of consent, in which the participants accepted the terms of the investigation.

Although I knew the participants' names, telephone numbers and e-mail addresses for arranging the schedules of telephone interviews, their identities were kept anonymous in the thesis. The personal identities of the participants were hidden in the questionnaire and interview answers, which were coded with course-specific ids. The contents of the discussions in the course forum stayed between the course members and the tutors, and I did not see them at all. This diminished the possibilities of the investigation, but it was the condition on which the participants accepted their participation in the investigation. Thus, the integrity and privacy of the participants were guaranteed.

7 DISCUSSION

In the Discussion chapter, I first compare the results of my investigation with Iriberri and Leroy's (2009) theory of online community life cycle and the online community success factors. This theory was published after publishing my papers, and thus I complement my socio-technical analysis, described in Section 5.4, with this comparison. Then I present the most important implications for science and practice of this investigation. In addition, I present the limitations of the investigation as well as some suggestions for future research.

7.1 Post-analysis of online community life cycle and success factors

Iriberri and Leroy (2009) recently wrote about the life cycle and the success factors of an online community. I post-tested and compared their findings with those of my investigation, and this consideration added to the life cycle perspective in this investigation.

Iriberri and Leroy "have labeled the five stages of the online community life-cycle as follows: inception, creation, growth, maturity, and death" (p. 13). They describe the success factors of each stage as follows (Figure 5): During *inception* stage, the idea of an online community emerges to satisfy the need for information, support, recreation or relationship. Some communities emerge when a small group of people with a similar interest, interact online, while others have born when an organization provides a platform for interaction. Success factors, such as purpose, focus and a code of conduct are necessary for all type of communities. In the *creation* stage, the creators select the technological components that will support the online community based on the needs of potential members and on the purpose of the community. In creating the community, creators must focus relentlessly on the needs of the users and must ensure that the tools are usable, that the supporting

platform is reliable, that the personal member information is secure, and that all technology components have an adequate level of performance. In the *growth* stage the community spreads, while a culture with an identity, a common vocabulary, a shared history, roles and rituals begin to surface. Iriberri and Leroy argue that in the *maturity* phase the communities mature into formal organizations, the creators and managers facilitate the formation of subgroups, and delegate control to volunteer subgroup managers. An important success factor in this stage is the recognition of the members' contributions. Mature online communities may sustain themselves and continue to grow and succeed, others change course, and a few cease to exit and thus reach the *death* stage.
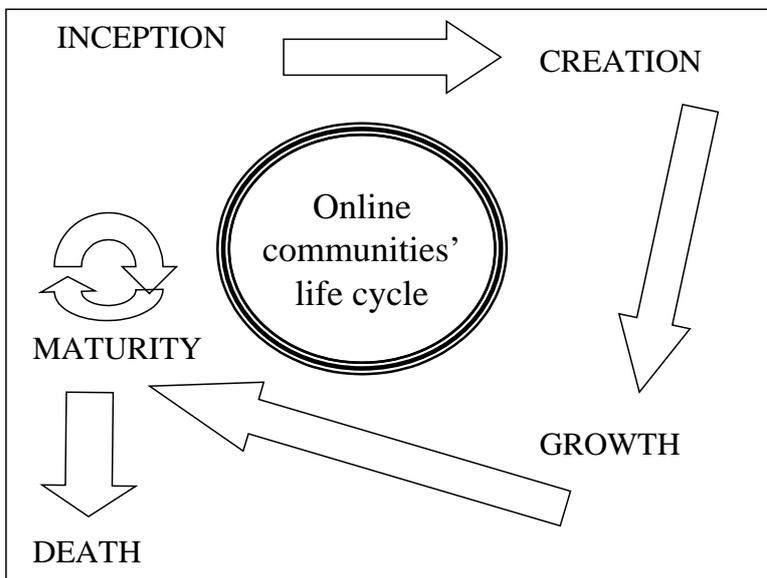
Figure 5. Iriberri and Leroy's online communitiy life cycle (p.14)

In comparing Iriberri and Leroy's online community success factors with the communities studied in my investigation, I found that there were some similarities (Table 7). Iriberri and Leroy's *inception* stage can be compared to the invitation phase of my investigation, where the preparations for the online community were performed: the community had a name, a focus, and a target group. The *creation* stage matches with my enrolment and start phases, where the technical environment was established, the kick-off meeting was held, the rules and security aspects were fixed and the first discussion themes were created. The *growth* stage can be compared to the discussions phase where the actual tutor-facilitated interaction

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started and the trustful atmosphere was created. Yet, though the growth did not concern the number of the participants, the trust became deeper and it stayed deep through the entire life cycles of the communities.

Table 7. Iriberri and Leroy's, and Heikkinen's virtual community life cycle

Virtual community by Iriberri and Leroy	*Virtual community by Heikkinen*
Inception - Purpose, focus, codes	Invitation to a course - Announcements, target groups, the goals of the courses
Creation - Usability, security, reliability, user-centered	Enrolment and start of a course - Kick-off meeting, learning the tool, first discussion topics, community policies
Growth - Quality content, trust, interaction, integration, new users	Discussions - Tutoring, interaction, deep trust, empathy, support
Maturity - Permeated control, subgroups, voluntary managers, events	The course discussions - Discussions without tutors, deep trust, support, empathy - Course 1 – two sub-phases
Sustainability or Death	End meeting – to continue or not to continue? - Course 1 – third sub-phase - Course 2 – ceased the exist

Iriberri and Leroy describe the *maturity* phase as a repeated phase where new life cycles may begin. The first course actually lived in three phases where the course was first for three months managed by tutors, second it continued for six months with tutors on the background, and after the course it continued without tutors at least for two years with the interaction taking place by group e-mail. The character of the community changed during the third phase from an actual peer support community to a community of chatting with friends, and the connection became more superficial and the activity decreased. The second course actually died immediately after the end meeting. The life cycle of the virtual communities studied followed Iriberri and Leroy's model from inception to death, with the first course actually repeating its life-cycle. The success factors of the communities proved to come true in my study supporting Iriberri and Leroy's theory in practice.

7.2 Implications for science

In this section, I describe the scientifically novel findings, the findings that support the earlier results, and those that contrast with the earlier results. The summary of the implications is listed in Table 8.

Table 8. The implications for science

Finding types	Implications
Novel findings	- Descriptions of the courses - Scenario of Internet courses as initiators for long-term virtual communities - New model for an Internet course - New Web 2.0 technology based discussion tool
Findings supporting earlier studies	- Confirmation of Preece's theory of virtual communities - Confirmation of people's role in a community - Confirmation of sociability and togetherness, trust etc - Confirmation of Resnick's theory of socio-technical capital
Findings contrasting with earlier studies	- Personal acquaintance vs. anonymity

7.2.1 Novel findings

In my investigation, I concluded four novel findings with scientific implications. The first one is how the descriptions of the two courses represent one type of a virtual community in real life – a small and closed community. The descriptions of the courses present the characteristics of the courses comparing Gregor's (2002, 2006) Type I: Theory for Analysing and Describing, and thus answer the question "what a course is". The results are described in detail in Paper1 and Paper2, where I concentrated more on sociability than usability.

The second novel finding was the scenario of an Internet course with a limited duration acting as an initiator for a long-term virtual community. The course participants expressed their wish to continue the interaction after the courses and did so by using group e-mail.

The wish to continue the interaction also led to the third novel finding: a suggestion for a model of an Internet course. The initial model of an Internet course is described in Figure 3 in Sub section 5.3.3, where the discussion tool should have been changed from Nettineuvola discussion forum to group e-mail. In the new model (Figure 6), all other phases are the same as in the initial model but there is a new tool that would remain the same throughout the community's existence.
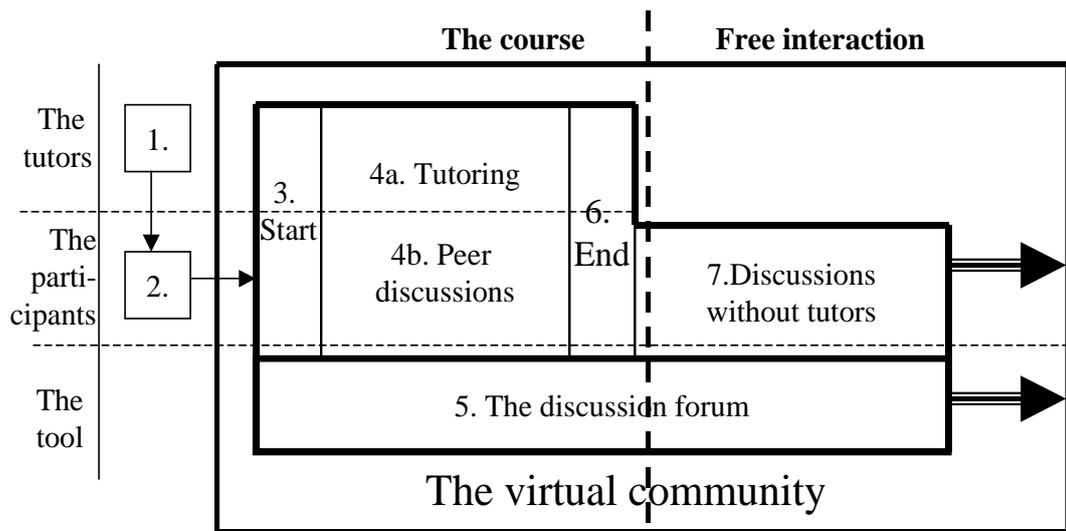

Figure 6. The proposed model of an Internet course

The fourth finding, which is related to the scenario and the model of an Internet course, is the suggestion of utilizing the modern Web 2.0- based technology as a discussion tool. Web 2.0 is such a wide and an ambiguous concept that it would need a separate analysis. In any case, it is a new paradigm by which the Web and social networking can be seen with new eyes. Web 2.0 offers social networking and sharing (Boyd and Ellison, 2007), user-contributed content and existing applications to create communities for discussion forums (Ovaska and Leino, 2008). Web 2.0 offers the possibility to share information in a more sophisticated way than Web 1.0, where the discussions were mostly textually engaged. When limiting the point of view to Internet courses, some aspects of Web 2.0 can be selected to apply them to the closed Internet groups. Web 2.0 tools enable discussions with texts, attachments, photos, videos, voice, and chatting in an up-to-date technical environment. Also environments such as Facebook, Twitter, LinkedIn etc. are easy to join. In them, there is the possibility to create groups that are accessible for only

those invited. Yet, the terms of privacy, safety, and security, as well as the possibility to delete the discussion history if desired, must be taken into account before deciding on the environment and implementing the discussion forum.

7.2.2 Findings supporting earlier results

In this investigation, there were four findings that support the results of earlier investigations. The first one confirms Preece's (2000) categories of virtual communities in testing them in a real virtual community environment. According to the results of my study, the communities fulfilled the features of Preece's criteria (people, purpose, policies, and computer). Thus, I can conclude that the participants created virtual communities, and Preece's criteria on usability and sociability were easily identified on the course.

The second finding that supports earlier results concerns the participants' roles in the course community that were detected when the two course communities were compared. This investigation can thus confirm Preece's argument: "*People* are the pulse of any community. Without them, there is no community" (Preece 2000, 82). People's roles on the courses proved to be problematic, because in spite of similar course circumstances, the course communities behaved differently: the ways of discussing were different, as was the degree of the participants' commitment. The interaction between the participants of the second course stopped when the course ended, but the first course continued their interaction for at least two years. In analyzing the reasons for the differences, I compared my results with Markus's (1983) three case study theories: People-determined, system-determined or interaction theory. I concluded that the dissimilarities between the courses mostly arose from the people-determined theory and were caused by the different set of participants. The participants on both courses were satisfied with the technical environment, which excludes the system-determined theory. The interaction theory is likewise excluded, because there were no organizational conflicts between the participants. The underlying assumptions of the people-determined theory are the factors internal to people and groups, and I argue that human nature and personality traits might have caused the differences between the courses. If the course

participants were changed, a new course with similar environment, organization and objective could behave in a new way that is different from any earlier courses.

The third finding that supports the results of earlier studies is the importance of sociability, togetherness, trust, empathy and support as the factors that maintain a community. Trust, empathy and reciprocity are the core building blocks that unite community members (Preece, 1999, Preece and Ghozati, 2001; Ridings et al., 2002; Lehto and Oinas-Kukkonen, 2009), which were strongly confirmed by the communities studied.

The fourth finding supporting earlier results is the confirmation of Resnick's (2002) theory on socio-technical capital that is based on Coleman's (1990), and Putnam's (1993) social capital theory combined with interaction on the Internet. In the cases studied, socio-technical capital is expressed through the high activity, the deep trust, the interaction in the communities, the shared knowledge, and common values and norms as well as through a shared sense of community. The amount of socio-technical capital was high during the life-cycle of the courses but it decreased after the courses, or even earlier when the tutors withdrew to the background. Also the character of the community changed from a close-knit support community to a more superficial chatting community.

7.2.3 Contradictory findings

In my investigation, there emerged one finding that was contradictory with the results of earlier studies: the importance of the personal acquaintance of the community members in order to reach deep trust. This is opposite to many earlier results (King, 1994; Joinson, 2001; Arnold et al., 2005; Krcmar and Leimeister, 2005) that argue for anonymity, and thus it is noticeable. Trust is an essential feature in a community's existence and deep trust comes from knowing each other. In addition to my finding, Chi et al. (2009) recently argued that offline social relationships can be important antecedents of success in the initial stage of developing online communities. When people encounter online others who they have previously met or cultivated offline connections with, and in whom they have grown to trust, they tend to be more participative, open and honest in the online

community. Thus, my finding may simultaneously be both a contradictory finding to and a finding that supports earlier results.

7.3   Implications for practice

In this section, I describe the implications of this investigation for practice: for the organizations that arrange rehabilitation courses, for the patients who take part on the courses, and for the ICT companies that develop discussion tools. The starting point of my study came from practice, and the results offer suggestions for future plans of rehabilitation courses for sufferers of MS or other long-term disease. Many implications seem to be comparable with the implications for science, but here I look at the results from the user perspective or from the point of view of course development. Summary of the implications for practice is listed in Table 9.

Table 9. The implications for practice

Arranging Internet rehabilitation courses is worth continuing
It is worthwhile to encourage the commitment of the course participants to improve the success of the community
It would be good to plan the courses already from the beginning as triggers of long-term virtual communities
The technical environment should be changed to support long-term existence of the community

It has been the most interesting looking at the main research question of this investigation – the feasibility of the Internet for MS patients' rehabilitation - from a practical point of view. The way of organizing the Internet courses seems to be successful, and arranging the courses is worth continuing. The kick-off meetings, the closed and relatively small discussion groups, the tutors as managers and the Internet itself form a suitable combination for a course construction.

There are some reservations when it comes to the feasibility of the Internet for rehabilitation courses. The use of Internet suits people who are comfortable of communicating by writing. People who prefer face-to-face contact may naturally opt out of Internet courses. The members of a virtual community are the most critical factor and most difficult one to predict when estimating the success of a course. Although the purpose, the policies, the technical and organizational

environments would be the same, the successful completion of the courses is not guaranteed, because the behavior of the participants is unpredictable. When selecting the course participants, it is worthwhile to consider the uncertainty the diverse personalities bring to the community, and to encourage the participants' commitment to the course.

The future Internet courses will have a limited length, but the course participants may wish to continue interaction even after the courses. Thus one basic objective of a course could be that it would work as a starting phase of a long-term virtual community that would exist as long as the community members wished.

Consequently of the previous implication for future rehabilitation courses, it is important to build the technical course environment and the discussion tool in a way that the virtual community created would technically be able to continue without a break between the course and the self-directed community. It is also important that the whole discussion database including the course history should stay available after the course. The new Web 2.0 based social media tool should be considered when planning new courses.

7.4   Limitations of the study and suggestions for future research

The method of this investigation was a theory-testing case study where I studied the cases in one context, which limits the generalization of the results. The number of the courses and persons studied was small, and further investigation of similar courses and comparison with the courses I studied could strengthen or contradict the results of this study.

The scope of the investigation was on one hand multi-disciplinary with aspects of Information technology, Medicine and Social sciences, but on the other hand the aspect of MS rehabilitation can be considered a limitation. Yet, the scope could be widened with approaching MS from other disciplines, e.g. psychology or learning theories, to study the behavior in virtual communities or the educational possibilities of Internet courses. The scope of the investigation could also expand by investigating the rehabilitation of other long-term diseases, such as cancer or diabetes.

Because of the strong demands of privacy, the contents of the discussions had to be left out of the study, which limited the possibilities to examine in depth the interaction between the participants. Extending the investigation to the contents of the discussions would offer better possibilities of deep content analysis and it could enrich the research results remarkably.

An interesting topic would be the results of acquaintance vs. anonymity to analyze in depth why the course participants so strongly emphasized knowing the other participants personally in contrast to many other studies that argue for anonymity. Studying Internet courses without a kick-off meeting might elucidate the acquaintance vs. anonymity issue.

Furthermore, a new topic might be to conduct a design research about Web 2.0 based discussion tools e.g. videoconferencing on a future course to study the effects of the latest technology on the action, success and life cycle of a virtual community.

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8 CONCLUSIONS

I summarize this thesis by concluding that I consider the most important novel implication of this study the description and the scenario of an Internet rehabilitation course as an initiator for a long-term closed virtual health care community that can give support, empathy, empowerment and information to its members in a trustful atmosphere. To support the long-term existence of a community, I presented a model for an Internet course that emphasizes the stability of the technical environment, but also suggests utilizing new Web 2.0 technology as the discussion tool. Finally, I described an example of a successful virtual community, which was created according to a plan, as opposed to an ad-hoc community, where people at first got acquainted face-to-face with each other. I presented new suggestions on exploiting virtual communities in health care and especially when it comes to patient peer support.

My investigation supports earlier theories of sociability and usability in virtual communities (Preece, 2000), the theory of socio-technical capital (Resnick, 2002) and some aspects of the theories on virtual community success (Iriberri and Leroy, 2009). Moreover, like Giddens (1989, p. 258) argues that the human agents always have the "possibility of doing otherwise", also here the diverse level of commitment and the uncertainty of people's behavior had unpredictable consequences to the community's action in spite of other permanent organizational and technical categories.

Online courses and virtual communities can offer a great deal in the fields of medicine, rehabilitation and training. However, ICT support is not fully utilized, and filling this deficiency has been one motivator of this investigation. This research indicates constructive ways and provides practical guidelines on how MS patients' rehabilitation programs can be re-organized efficiently. The results of this investigation are of great importance in the area of Information and Communication Technology, especially in the context of virtual human-centered technology for the advancement of the information society. Online courses and virtual communities'

support can be considered as facilitators of welfare and sociability in a human-faced technology society. The practical dimensions of the problems that are called to solve – such as the rehabilitation of MS patients – are only a few of the humane aspects of ICT that socio-technical approaches could provide people with. Moreover, the findings are also significant for Internet-based rehabilitation of other long-term diseases.

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APPENDICES

Appendix 1a – Information letter

Power and Support from the Net Course

Have you recently been diagnosed with MS and would you like to share experiences, obtain information and discuss with people in a similar situation? In the autumn 2005, The Finnish MS Society's Northern and Lake Side Outpatient Rehabilitation Centres will arrange an Internet rehabilitation course. The purpose of the course is to offer a discussion forum to people, recently diagnosed with MS and help them to adapt to their new situation.

The course offers:

- a possibility to exchange and share experiences, thoughts and feelings about living with the disease
- a possibility to find answers to questions about MS from other people in the same situation
- current information on the disease, its cure and rehabilitation.

An Internet course means a closed discussion group on the Internet, which the users log in with a user-id and password. The group is managed by two tutors, who also participate in the discussions. The participants will get acquainted each other in a one-day face-to-face meeting, where the discussion themes and policies will be decided. The meeting will take place in October 2005 either in Oulu or Kuopio. The applications should be sent in by September 31, 2005.

Appendix 1b – Course 1 – Questionnaire1, start of the course, 21st Nov 2005, the participants

Gender?

Year of birth?

Profession?

Occupational status?

Your living situation? – alone / with family / in a care facility / other

Reason to participate the course?

Expectations of the course?

Advantages of Internet vs. face-to-face courses?

Deficiencies of Internet vs. face-to-face courses?

Earlier experiences?

Other rehabilitation or adaptation courses?

Contacts with other people with MS?

Participation in MS associations or clubs? Activeness?

Limitations in using a computer?

Years in using a computer?

The place of the computer?

Earlier use of the Internet (e-mail/Internet browser/MS Society's discussion groups/banking services/electronic community transactions/net shopping/other active Internet use/no previous experience)

Appendix 1c – Course 1 – Questionnaire2 at the end of tutored phase, 28th Feb 2006, the participants

Computer

What kind of Internet browser have you used during the course?

What kind of Internet connection have you used during the course?

What do you think about Internet security in a course environment?

What kind of risks do you think there can be in Internet security?

Nettineuvola Program.

How long (days, weeks, tutorials) did it take for you to learn to use the Nettineuvola program?

Did your way of using Nettineuvola change during the course? How?

Do you think Nettineuvola is functioning fast or slow?

How did the fastness or slowness affect your activity during the course?

Have you come across error situations when using Nettineuvola? How have you coped with those situations?

Do you think it is easy to find new, previously unread messages in Nettineuvola?

Do you think it is easy to post new messages in Nettineuvola?

Do you think it is easy to navigate from a discussion thread to another?

What do you think about the Nettineuvola interface (clear, consistent, easy to understand, etc.)?

What are your wishes and suggestions for developing Nettineuvola?

Purpose

What are the best things the course has offered you?

Do you feel that there was something missing from the course? What?

Do you think that there was something irrelevant in the course? What?

How much help did you get concerning the symptoms of MS?

How much help did you get concerning medical care of MS?

How much help did you get concerning medical rehabilitation possibilities of MS?

How much help did you get concerning social rehabilitation possibilities of MS?

How many replies did you receive to your own questions?

People

What do you think the course community gave you?

What do you think you gave to the course community yourself?

What kind of roles do you think developed within the group (i.e. manager, discussion starter, active poster, commentator)?

What do you think was mostly your role during the course?

What do you think was your role the least during the course?

What do you think about the role of the tutor during the course?

During the course, did you feel you were part of a group or did you feel you were working individually?

What kind of things made you interact more with the others?

What kind of things, if any, distracted your interaction with the others?

Have you been in touch with the course participants outside Nettineuvola during the course? If you have, specify how (e-mail, chat, telephone, or meeting), and how often?

Would you like to stay in touch with the course participants also after the course? Why?

How would you compare an Internet course to a "face-to-face" course? Has your opinion of Internet courses changed to more positive or more negative?

Policies

Do you think the tone of the discussions has been appropriate?

Has the tone of the discussions changed during the course and how?

How has working with your own user-id (vs. anonymous) affected your participation in the discussion?

If you wish, list here more impressions and feelings you have had during the course. Continue to the other side of the sheet if necessary.

Appendix 1d – Course 1, Interview1 at the end of tutored phase, March 2006, the tutors

Overview

Describe the enrolling process?

Give an overview of the course and its success?

Which were the facts concerning the activity as numbers of themes, messages etc?

Computer (technical questions)

How did the technical environment function?

How well could the participants use the Nettineuvola program?

Were there any requests for help from the tutors in technical matters?

Were there any proposals for developing the Nettineuvola programme?

Purpose and meeting the goals

How the goals were met from the tutors' (MS Society's) point of view?

What was the best on the course?

Was there something missing from the course?

People (interaction)

Did the participants form a community or did they work as individuals?

What kind of roles there existed?

How would you describe the participants' activity in general?

How was the trust demonstrated?

Policies

What was the tone of the discussion? Were there any changes?

Was there ever need for intervention?

Lessons learned

Should a similar course be arranged in the future or not? Why/why not?

What should be done differently?

Appendix 1e – Course 1 – Questionnaire3 at the end of the course, 28ᵗʰ Aug 2006

Computer

How did your computer and software work during the course? Did it have an effect on your own participation during the course?

How well do you think the Internet as a tool suits a rehabilitation course?

Do you have any suggestions for future Internet courses and their new participants?

What do you think about an online real-time video connection as a tool for an Internet course?

Purpose

Did the course meet your expectations?

Did the themes of the discussions change after the tutors left the course? How?

Did you think the course gave you more than previous courses you have participated? What?

People

Was there a change in the discussion activity after the tutors left? If so, what kind of change?

Was there a change in your own activity after the tutors left? If so, what kind of change?

What do you think might have been the reasons for the possible change in the activity?

How do you feel about the ending of the course?

Do you believe the group will exist after the course or will the final course meeting be its last one?

Have you planned to stay in touch with the other course members after the course?

Policies

Did the tone of the discussions change after the tutors left? How?

Have there been changes in the openness of the discussions since the tutors left?

Appendix 1f – Course 1 – Interview2 at the end of the course, Sep 2006, the participants

Overview

What is your situation after the course? Do you maintain contact with other participants?

Your activity?

What did you get from the course?

What was the tutors' role in your opinion?

Have you joined other online groups?

Greetings to the participants of future courses.

Appendix 1g – Course 1 – Interview3 at the end of the course, Nov 2006, the tutors

Final facts?

How the goals were met from the MS Society's point of view?

Were there any differences between phases 1 (tutor moderated) and 2 (tutors on the background)?

Were there any changes during the course?

Lessons learned? Why did the course succeed so well?

Appendix 2a – Course 2 – Questionnaire at the end of the course, Apr 2007, the participants

Basic information

Gender? Male/female

Year of birth?

 Profession?

Occupational status? Working / student / stay-at-home / unemployed / sick leave/ part-time retired / retired / other (please specify)

How do you live? Alone / with family / in a care facility / other (please specify)

Do you have any MS-related limitations or special needs in using a PC?

Do you use any aids with a PC to diminish the limitations caused by MS?

How many years of experience do you have in using a PC?

Where do you use your PC? At home, at work, in a library etc.?

Which following uses of the Internet are familiar to you? e-mail / Internet browser / MS Society's discussion groups / banking services /community services/net shopping / other active Internet use / no previous experience in using the Internet?

Computer

Technical environment

Which Internet browser did you use during the course? Microsoft Explorer / Netscape / Mozilla Firefox / other (please specify) / I don't know

What kind of Internet connection did you have in the course? broadband / modem / I don't know

How well did the Internet connection work during the course? well / variably / poorly

How do you think the Internet security worked during the course? well / moderately / poorly / I can't say

Did you detect any security threats during the course? If so, what kind or threats?

In your opinion, how does the Internet suit a rehabilitation course?

What is your opinion of an online video connection's (e.g.. Skype) suitability as a rehabilitation course tool?

Nettineuvola Program

How long did it take before you could use Nettineuvola? days / weeks

Did your way of using Nettineuvola change during the course – If it did, how?

How did the fastness/slowness of Nettineuvola use affect your participation in the course?

Did you come across any error situations in using Nettineuvola and how did you manage them?

Did you have to use the Help command in Nettineuvola and how did it affect your use?

Did you need to ask the tutors or other course participants for help in using Nettineuvola? How did asking help work in your opinion?

How easy is it finding new messages in Nettineuvola? 1 (easy) to 5 (difficult)

How easy is it writing new messages in Nettineuvola? 1 (easy) to 5 (difficult)

How easy is it to navigate between discussion themes in Nettineuvola? 1 (easy) to 5 (difficult)

What do you think of the Nettineuvola user interface? Was it easy, consistent, easy to understand etc? 1 (easy) to 5 (difficult)

What kind of wishes or proposals do you have to enhancements of the Nettineuvola program?

Purpose

What made you come to the course?

What made you keep up on the course?

What were your expectations and wishes from the course in the start of the course?

How have your expectations and wishes come true during the course?

What is the best the course offered you?

Was the something you missed? What?

Were any irrelevant topics discussed during the course? Which?

Did this course give you more/less than possible earlier courses? What?

How much help did you get concerning the symptoms of MS? 1 (enough) to 5 (none)

How much help did you get concerning the cure of MS? 1 (enough) to 5 (none)

How much help did you get concerning medical care of MS? 1 (enough) to 5 (none)

On which areas of medical rehabilitation did you get information? Physiotherapy / outpatient rehabilitation / institutional rehabilitation / equipment / other, which?

How much did you get information on the social rehabilitation possibilities of MS? 1 (enough) to 5 (none)

On which areas of social rehabilitation did you get information? Rehabilitation and KELA (The Social Insurance Institution of Finland) subsidy / reimbursements for medicine expenses / advice for pensions/communal services/other, what?

Did you receive answers to your own questions? 1 (enough) to 5 (none)

People and interaction

Do you have many contacts with other people with MS?

What did you get from the course community?

What did you yourself give to the course community?

What kind of roles there were in the community? Manager / discussion starter / active poster / commentator / reader

What do you think was mostly your role during the course? Manager / discussion starter / active poster / commentator / reader

What do you think was your role the least during the course? Manager / discussion starter / active poster / commentator / reader

What do you think about the role of the tutor during the course?

Did you feel like a part of the group or did you feel like you worked as an individual?

How was the individualism / sense of community demonstrated in the group's action?

What, if anything, distracted your interaction with other participants?

Have you been in touch with the course participants outside Nettineuvola during the course? If you have, specify how (e-mail, chat, telephone, or meeting), and how often?

Were you willing to continue communication with other participant after the course as well? Why?

How was the mutual trust demonstrated in the discussions?

Internet rehabilitation vs. face-to-face rehabilitation

Have you been to other group rehabilitation or adaptation courses organized by the MS Society? When and what course?

Which advantages do you think you got from Net rehabilitation vs. face-to-face rehabilitation?

Which shortcomings do you think there are in Internet rehabilitation vs. face-to-face rehabilitation?

Has your attitude towards Internet courses changed to more positive or negative direction?

Would you take part in a face-to-face rehabilitation course? Why/why not?

Was the length of the course convenient or should it be longer?

What about the future? Do you think that the group will stay in touch or will the communication end together with the course?

What about the future? Will you continue interaction in some way with other course participants?

Purposes

Do you think the tone of the discussions was positive? 1 (very positive) to 5 (very negative)

Has the tone of the discussions changed during the course and if it has, how?

How has the trust shown in the discussions during the course?

How has working by user-id (known user) affected your participation in the discussions?

Would it be more comfortable / more uncomfortable to be an anonymous user on the course? Why?

If you wish, continue here sharing your ideas and feelings.

Appendix 2b – Course 2 – Interview at the end of the course, May 2007, the participants

How do you feel now after the course?

Was the course's length adequate or would you have wanted to continue?

What did you get from the course?

Did you get what you were expecting from the course?

Have you kept in touch with the other participants?

Have you joined other online discussion groups?

Did the course change your attitude towards other discussion groups?

Could you join a course without seeing other participants in advance?

Has the course changed your attitude towards MS?

How do you see the tutors' roles now?

Which were your greetings to the new courses / participants?

Appendix 2c – Course 2 – Interview at the end of the course, June 2007, the tutors

About the participant selection process: Were there many candidates? How were the participants selected?

How were the MS Society's goals fulfilled? What was especially good on this course? What would you do differently?

Which were the activity numbers?

What do you think about the need to continue the interaction after the course?

Should the interaction be arranged by group e-mail or other way?

Compare this course to the earlier Power and Support courses.

Appendix 3a – Courses 1 and 2 – Questionnaire after the courses, Jun 2008, the participants

Everybody answers questions 1 – 3.

1. What is left of the group after the courses?
2. Have you joined other MS discussion groups and what are your experiences of them?
3. What do you now think about acquaintance vs. anonymity on the courses?
4. Do you have any comments on the course, the community's action, tools etc?

If you are still along with the group, please answer the questions 5-12.

5. Why do you think your group is still active?
6. Why are you still along?
7. How active are you in the group?
8. How has the tool change from Nettineuvola to group e-mail affected the groups' action?
9. Have the discussion topics or policies changed? How?
10. Have the roles changed? Has somebody become a leader?
11. Have you used other discussion tools: telephone, chat, skype, face-to-face meeting etc.?
12. Do you have any plans for the future of he group? What kind?

If you continued after the course but left the group later, please answer the questions 13-15.

13. How long did you stay with the group and how active were you?
14. Why did you leave the group?
15. How did the tool change from Nettineuvola to group e-mail affect the groups action?

If you have not been along since the course ended, please answer the questions 16-17.

16. Why did you decide to stop of the interaction immediately after the course?
17. Did the tool change from Nettineuvola to group e-mail affect your decision?

Appendix 3b – Courses 1 and 2 – Interview after the courses, Jul 2008, the participants

Is your course group still active?

Have the discussion topics changed? Do you discuss MS or something else?

Does somebody act as a manager or as an active poster?

Has your attitude towards MS or life in general changed during or after the course?

Did you course group stop communicating when the course ended?

Have you been in contact with any other participants after the course?

Have you joined other discussion groups after the course? If so, were you inspired by the course?

Do you miss something from the course?

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