

USER INVOLVEMENT IN DESIGNING A WEB-BASED SUPPORT SYSTEM FOR YOUR CARERS

-inspiring views and systemic barriers

Mikael Elf

Department of Psychology
Sweden
2013



UNIVERSITY OF GOTHENBURG



Mikael Elf

Printed in Sweden by Ineko

Göteborg, 2013

ISSN 1101-718X

ISRN GU/PSYK/AVH—275—SE

IISBN 978-91-628-8672-1

The e-published version of this dissertation: <http://hdl.handle.net/2077/32548>

“The proper study of mankind is the study of design...”

Herbert A Simon

DOCTORAL DISSERTATION IN PSYCHOLOGY, 2013

Abstract

Elf, Mikael. (2012). *User involvement in designing a web-based support system for your carers - inspiring views and systemic barriers*. Department of Psychology, University of Gothenburg, Sweden.

The studies in this dissertation have their origin in the research project PS Young Support. This project aimed to develop and evaluate a web-based support system (WBSS) for young people living close to someone with mental illness. To make this support relevant, and to achieve legitimacy and trustworthiness it was found important to cooperate with prospective users in developing it through a participatory design (PD) process. The dissertation follows two lines of investigation. One of these relates to how PD can inspire new views on design, while the other is about barriers to involvement of users. Specifically, inspiring views aims at how a PD process with prospective users as co-designers has inspired a new way to think about WBSSs. Moving on from the common idea of a WBSS as a stand-alone intervention, Studies I and II show that WBSSs can be used as a tool to reach real-life support. Earlier research suggests that online support is rarely the preferred support; the present research show that young carers viewed it as a starting point for reaching real-life contacts and real-life support.

Furthermore, young people with poor mental health are more prone to seek support online compared with those with less poor mental health. Hence, a WBSS could serve as a means to capture the former group and offer them online support. At the same time it could serve as a tool for reaching real-life support and external services. In this way the WBSS could offer a help path to individuals in need of support. Study IV investigates meta design, i.e. how users have really used the WBSS and the conditions for redesign. The development WBSS and its implemented version are compared with respect to their intended use (thing design) and how they really were used (use design). The context of use was found to be critical, since data collected in an experimental setting may be misleading and not reflect real use. Consequently, natural settings are recommended for user feedback.

The second line of investigation in this dissertation concerns systemic barriers including barriers to user influence. It is not common in PD to focus on the designers. However, Study II and III reveal two types of barriers, both of which are connected to the designers. They are “systemic” barriers as they are a part of the setting that constitutes design. They cannot really be avoided, just handled. The first barrier has to do with the fact that users and designers do not regularly share the same social conditions, and consequently that they have different assumptions, implying that they may have difficulties to understand each other. Assumptions of shared views and the fact that understanding is a process that takes time may increase the effect of this

foundational difference. Study II reports crucial differences in the views of what the WBSS should support. The second barrier concerns the impact of deadlines on designers' attitudes to users' contributions. Study III reports that halfway through the design process, designers reorganized their work and put more effort into the act of producing an artefact. Along with this shift, designers' preferred type of knowledge seemed to change, from knowledge based on user experience to expert knowledge.

Keywords: Design process, meta design, online support, participatory design, public, user involvement, web-based health support, young carers

POPULÄRVETENSKAPLIG SVENSK SAMMANFATTNING

Denna avhandling handlar i grunden om design, där tänkbara användare har varit delaktiga i designprocessen, i detta fall en participativ design (PD). Mer specifikt handlar den om hur användare varit med och utformat ett webbaserat stöd riktat till unga som är närstående till någon med psykisk ohälsa. Design i denna mening handlar inte bara om utseende och layout, snarare ligger fokus på funktion. Avhandlingen omfattar hela cykeln från att lära känna de tänkta användarnas situation och behov och vidare till utvecklingen av det stödsystem som kan tänkas svara mot dessa behov för att slutligen landa i implementeringen av stödsystemet i verkliga livet.

Avhandlingen har två spår. Det ena handlar om hur de användare som deltagit i designarbetet tillsammans med forskare/designers inspirerat till nya sätt att tänka kring ett sådant stöd (Studie I och II) och hur "riktiga" användares faktiska användning kan tas tillvara för att bättre anpassa stödet (Studie IV). Det andra spåret handlar om de hinder gentemot användarinflytande som funnits inbyggda i själva sättet att arbeta på (Studie II och III).

Gruppen unga, 16-25 år, som har närstående med psykisk ohälsa är på många sätt hårt belastade. Rapporter visar att denna åldersgrupp generellt mått allt sämre de senaste decennierna. Som tänkbara orsaker har angetts samhällets ökade individualisering, dvs. att allt mer ansvar förläggs på individen, liksom svårigheten för många unga att komma in på arbetsmarknaden. Ungdomar i denna grupp kan komma att söka stöd från kamrater som då får hantera ibland svåra tillstånd, t ex självmordshot. Ungdomarna kan också själva vara stödjare åt både kamrater och andra närstående, vilket ytterligare ökar belastningen på dem samtidigt som de generellt sätt har lite stöd från samhället.

Eftersom unga personer tillhör den grupp i samhället som allra mest använder nätet faller det sig naturligt att utveckla webbaserade stöd till dem. Generellt har det visat sig att personer som söker fakta om sjukdomar på nätet mer ofta söker information därför att en närstående har problem än att man gör det för sin egen skull. Det visar sig också att de som söker hälsoinformation på nätet oftare söker hjälp via vården och att de som specifikt söker information om en närståendes sjukdom är mer benägna att söka stöd. När det då gäller gruppen unga som är närstående till någon med psykisk ohälsa så skulle man då kunna säga följande: 1) i och med att de är unga så använder de nätet mycket, 2) eftersom de är närstående är de benägna att söka hälsorelaterad information och 3) eftersom de söker hälsorelaterad information och är närstående är de över huvudtaget mer benägna att söka stöd och hjälp. Trots att detta verkar tala för webbaserade stöd så har det funnits begränsat med forskning om stöd till unga via nätet och i stor sett ingenting som har rört unga som har närstående med psykisk ohälsa.

Studierna som redovisas i denna avhandling bidrar till att fylla en del av detta

tomrum och baserar sina bidrag på vad designprocessen gett och på en kritisk analys av densamma. I Studie I intervjuades tolv unga (16-25 år) som själva stödde en närstående och syftet med studien var att utforska de stödbehov som ungdomarna hade i de situationer de befann sig i. Denna studie blev en bas där vi som forskare fick en inblick i deras vardag som stödjare. Stöderfarenheterna varierade ifråga om hur länge man hade stött, hur ofta man stödde, vem personen var man stödde och viken typ av symptom denne hade. Man kan dock konstatera att ungdomarna överlag hade en hög belastning. De tillfrågades även om hur de tänkte sig att ett webbaserat stöd skulle fungera. När det gällde stödbehov framkom tre områden som väsentliga: att få kunskap (om psykiska sjukdomar, om hur man hanterar den sjuke, om hur man tar hand om sig själv), att kunna kommunicera med andra (utbyta erfarenheter, få råd och stöd, skaffa vänner) och att få direkt hjälp utifrån (akut avlastning, mer långsiktigt familjestöd, mer ansvarstagande sjukvård). Deltagarna i Studie I ansåg att webbaserade stöd kan fungera som en bas och en början till stöd ”i verkliga livet”. Det är en synpunkt som återspeglas i flertalet studier om internetbaserade stöd, nämligen att både yngre och äldre generellt föredrar ”verkligt” stöd. I nästa steg, Studie II, deltog åtta unga, varav sju från Studie I, alla med erfarenheter av att vara stödjare. Här studerades själva designprocessen. Ungdomarna delades upp i två grupper. En grupp arbetade tillsammans med två forskare och en systemutvecklare under fem designmöten fram det webbaserade stödet, medan den andra gruppen löpande granskade detta arbete utifrån. Detta tog sammanlagt åtta månader och pågick från november 2009 till juni 2010. Studien gav dels kunskaper om vilka delar som var viktiga i ett sådant stöd men också insikten om att ungdomarna och forskare/systemutvecklare hade vitt skilda idéer om väldigt grundläggande saker, som t ex vad stödet egentligen syftade till och på vilket sätt det skulle stödja. Ungdomarnas såg framförallt stödet som något som kunde hjälpa dem att hjälpa deras närstående, medan forskarna i första hand så stödet som en hjälp till de unga själva.

I Studie III granskade vi det arbete som skedde mellan designmötena i designteamet. PD strävar ju efter att bedriva designarbetet tillsammans med användarna, vilket mer naturligt låter sig göras på t ex en arbetsplats där också PD har sina rötter. I ett sådant fall finns användarna dagligen tillgängliga och ett gemensamt utvecklingsarbete underlättas. I Studie III var sammanhangen annorlunda. Ungdomarna deltog på sin fritid, något som alltså konkurrerade med t ex studier, fritid och deras roll som stödjare för en närstående. Deras deltagande måste alltså bli betydligt mer begränsat och förutsättningarna för ett gemensamt designarbete annorlunda. Designteamet bestod av två forskare och två professionella systemutvecklare. Syftet med studien var att undersöka misstanken om att designteamet i sin avskildhet utvecklade egna tankar om hur stödet skulle utformas och fungera, vilket skulle inverka på användarnas inflytande. Eftersom designteamet uteslutande

kommunicerade via mail, då de fanns på olika fysiska platser, så studerades denna kommunikation. Den kompletterades också med en gruppintervju. Det visade sig att det fanns problem för designteamet att förhålla sig till användarna, men att detta framförallt berodde på design processens inbyggda tidsramar. Det verkade ske en relativt dramatisk förändring i andra halvan av processen. Efter att inledningsvis varit mycket öppna i förhållande till användarna så ställde designteamet om sig och blev fokuserade på att åstadkomma en produkt. Detta ledde till en omdirigering av deras resurser och sätt att arbeta där logistik och produktivitet prioriterades på bekostnad av fokus på användare. Vidare verkade detta nya förhållningssätt också påverka designteamets attityder, där man alltmer kom att betona vikten av expertkunskap och allt mer kom att ifrågasätta användarnas kunskap. I avhandlingen kallas de hinder för användarinflytande som Studie II och III lyfter fram för "systemiska". Det syftar på att de är en del i villkoren för participativ design – de kan därigenom inte undvikas utan bara hanteras.

Även om PD oavsett inbyggda svårigheter har stora chanser att bättre svara mot de riktiga användarnas behov än om man inte engagerat användare, så går det inte helt att förutse vad de riktiga och framtida användarna tycker. Studie IV undersökte förutsättningarna för omdesign i två olika sammanhang genom att använda webbstatistik. Webbplatsen som utvecklades för den experimentella studien (som kommer att redovisas i annan avhandling), Molnhopp.nu jämfördes med den webbplats som implementerats i "verkliga livet", Livlinan.org. Det sätt på vilket innehållet hade profilerats jämfördes med avseende på hur det verkligen hade använts. Slutsatsen var att användningen var relaterad till sammanhanget och till användarnas behov. Användningen i det experimentella sammanhanget verkade präglad av just detta sammanhang medan användningen i det naturella sammanhanget verkade styrt av användarnas behov. Studien drar slutsatsen att webbstatistik som ska användas för omdesign måste hämtas från en verklig användarmiljö och att omdesign framförallt handlar om att anpassa innehållsprofil till användningsprofil.

ACKNOWLEDGEMENTS

There are many people to whom I would like to express my gratitude. This especially concerns my supervisor professor Annika Dahlgren Sandberg and second supervisors PhD Barbro Krevers and associate professor Hans Rystedt. Together they have made the writing of this dissertation possible and I sincerely appreciate their outstanding support.

According to Bruno Latour and actor network theory actions are distributed and it is quite impossible to say where an action begins and where it ends; this goes for writing to. Writing a dissertation involves a network of people contributing and affecting each other in different ways.

A fundamental part of this network was the research project of which I became a part. It consisted of the project leaders professor Ingela Skärsäter and PhD Barbro Krevers, my PhD-student colleague Lilas Ali and our communications officer Pia Mattzon. We have had both hard work and nice times together! Co-workers during the planning activities was FoU Sjuhärad and the project was funded by The Vårdal Institute, Vinnova and GU.

Likewise fundamental was of course the co-writers of my articles of whom all have been mentioned except Johan Lundin, associate professor at Department of Applied Information Technology, GU.

The twice a year workshops at the Vårdal Institute with PhD student colleagues and senior researchers have been outstanding both as a “sandbox” for practising research and for pleasant relaxation. On my home department, I have especially appreciated the HHÅ group (health, handicap and aging) meetings and in the last year the CPR (Clinical Psychology Research) meetings.

Other people who in different ways have contributed to this dissertation are professor Pelle Ehn, professor Ann Frisé, professor Hans Glimell, PhD Britt Hedman-Ahlström, associate professor Elisabet Wentz and several proficient anonymous reviewers. Equally important was the collaboration with PhD student and system developer Daniel Rudmark, systems architect Marcus Blomberg (both on Innovation Lab at the time) and programmer Remy Dodin.

There are also people who not explicitly was related to my dissertation, but have inspired and extended my thoughts. I especially think of professor Tom Postmes at University of Groningen and the researchers at Knowledge Media Research Center (KMRC) in Mannheim, whom I met during a workshop arranged by KMRC. Their research in the domain of social identity theory has a great significance for how to understand online behaviour.

I am deeply grateful to the study participants whose contributions were

invaluable. Without them there had been no studies at all.

On the more personal level I wish to thank David Wahlstedt for his support during the whole process, including both nice and more harsh, but always concerned, comments :-).

Finally, I would like to thank my family, my wife AnnaCarin and my children Kalle and Maja, for being with me through this process and for being my family. I love you!

A golden rule when designing error messages in computer software is to ensure that they never blame the user. I would like to apply this principle also in this acknowledgements part. Therefore, if you feel that you have contributed to this dissertation but not has been acknowledged, it is not because of you. Rather, it is because of my limited ability to, in this very moment, retrieve from my memory all important contributors. Thank you all!

The dissertation is based on the following studies, referred to by their roman numerals.

- I. Elf, M., Skärsäter, I. & Krevers, B. (2011). "The web is not enough, it's base" – an explorative study of what needs a web-based support system for young carers must meet. *Informatics for Health and Social Care*, 36(4), 206-219.
- II. Elf, M., Rystedt, H., Lundin, J. & Krevers, B. (2012). Young carers as co-designers of a web-based support system - the views of two publics. *Informatics for Health and Social Care*, 37(4), 203–216.
- III. Elf, M., Rystedt, H. & Krevers, B. (20XX). *Handling user influence in participatory design – a grounded theory study of the internal work of a design team*. Manuscript submitted for publication.
- IV. Elf, M., Rystedt, H., Skärsäter, I. & Krevers, B. (20XX). *A comparison of intended and real use of a research web health portal and its implementation*. Manuscript submitted for publication.

Content

Introduction.....	1
New media and young people.....	2
Young carers.....	3
Online support and its components.....	6
Knowledge acquisition.....	6
Social support.....	7
Web-based support.....	8
Perspectives on design.....	11
Design as a social process.....	13
Group processes in design teams	14
Distributed design environments.....	15
Involvement of users.....	16
Participatory design.....	17
Communities of practice	19
Well and less well structured contexts.....	20
Dewey's concept of public.....	21
Meta design.....	23
Gaps in current research.....	25
Summary of studies.....	26
General aims of the dissertation	26
Context of the studies.....	26
Study I.....	28
Aim.....	28
Participants and setting.....	28
Data collection.....	28
Data analysis.....	29
Results.....	29
Conclusions.....	30
Study II.....	30
Aim.....	30
Participants and setting.....	30
Data collection.....	31
Data analysis.....	31
Results.....	32
Conclusions.....	33
Study III.....	33
Aim.....	33
Participants and setting.....	34

Data collection.....	34
Data analysis.....	34
Results.....	35
<i>Qualitative analysis</i>	35
<i>Quantitative analysis</i>	36
<i>Theoretical model</i>	37
Conclusions.....	38
Study IV.....	39
Aim.....	39
Setting.....	39
Data collection.....	39
Data analysis.....	39
Results.....	40
<i>Profiles of intention</i>	41
<i>Profiles of use</i>	41
Conclusions.....	43
General discussion.....	45
Users' perspectives and implications for design.....	45
From treatment to tool.....	48
Conditions for user influence.....	50
Implications for the design process.....	52
Reflections on methods	53
Participants.....	53
Data collection.....	54
<i>Sensitive settings in data collection</i>	55
Data analysis and results.....	56
Ethical considerations.....	57
Concluding remarks.....	58
Future research.....	59
References.....	61

Preface

When I was a young psychology student, we had a several lectures on Leuner's symbol drama or guided affective imagery (GAI). This is a psychotherapeutic method which is based on the assumption that intra-psychical problems are processed at a subconscious level and which could be described as making use of controlled day dreams. Conventional methods of relaxation are used to evoke a suggestive condition in the client. The therapist then evokes pictures of a landscape, e.g. beginning with a meadow, and guides the client whenever he or she is confronted with obstacles on the way. During one of these sessions our lecturer wanted to show us something important. As usual during these sessions, our group were split into pairs and working in different rooms. One of us was assigned the therapist role and the other the client role. After each session we used to reassemble and discuss different perspectives of our way of handling problems during the session and how we could develop our skill. This time, however, the "therapists" among our group were let into the room first. We were asked to paint a picture of how we imagined our "clients'" landscape in the GAI session on the blackboard. After that we had to leave the room and the "clients" were let in. After a while the whole group were reassembled. When we came in again we saw that our own drawings had been covered with a sheet of paper and that a drawing by the "client" had been added beside. The paper covers were removed and we could view pairwise two pictures of the same session. Were they alike? No, of course not! There were similarities, but not far-reaching ones, and not in between every pair.

This little experiment showed us that although we, as therapists working together with the client, felt that the cooperation was good and that we understood the client, our views of the "landscape" were quite different. This doesn't necessarily mean that our views were entirely different and that these views could not be aligned through dialogue. However, it suggests that assumptions of shared views, based on a seemingly cooperative climate, have to be scrutinized and viewed with a critical eye. This dissertation is strongly influenced by the ideas above, but in the context of participatory design (PD) and the relationship between designers and users.

Introduction

This dissertation and the studies in the dissertation have their origin in the project called PS Young Support. This project aimed to develop and evaluate a web-based support system (WBSS) for young people living close to someone with mental illness. It was started by researchers at the Vårdal Institute, Sweden, based on the fact that close others often have to carry many of the consequences of mental illness, with little or no support. Furthermore, the researchers found it important to focus on young close others, who had been reported to express strong dissatisfaction with the support offered by psychiatric health care (Östman, 2000). Another reason for focusing on a younger group was a published report (SOU, 2006) pointing out that young (i.e. 16–25-year-old) people's mental health in general had worsened over the last decades, possibly due to an increased individualization in society and decreased opportunities for young people to enter the labour market. Living close to a mentally ill person could accordingly serve as an additional strain to already exposed young persons, making it vital to develop new forms of support as a matter of urgency.

To make this support relevant, and to achieve legitimacy and trustworthiness it was found important to cooperate with prospective users in developing it. We wanted to explore their needs and collect their thoughts and ideas about a WBSS. Moreover, we wanted to involve them in the design of that support. By choosing this approach we adhered to the type of participatory design (PD) research that Törpel (2005, p. 178) labels "PD by occasion".

However, involving users is not without complications, which is why the design process itself also had to be scrutinized. The aim of this dissertation was to explore users' perspectives and user influence in a PD process, thus contributing two types of knowledge. The first of these relates to the design of the WBSS. It (1) explores young carers' views and ideas from their perspective both as prospective users and as co-designers and (2) explores conditions for redesign in an experimental versus a natural setting. The second type of knowledge relates to the design process itself and explores the conditions for users' influence as a function of users' and designers' different social conditions and as a function of the designers' internal work and the conditions for their work. In all, the dissertation explores how user

involvement can inform design and what barriers to involvement can be expected.

New media and young people

New media, such as mobile devices and computers, play a prominent part in the life of young people. Broddasson (2007) has shown, using data from a longitudinal study in Iceland, that the new media have rapidly grown and established themselves as the media of youth, to replace books and newspapers. Television is still holding its position but its use has become more individualized and possibly television is on its way to being reduced to a background medium (Broddasson, 2007). A central characteristic of the new media is connectivity. In Sweden, Internet connectivity at home is available to 83% of the population, while in the age group 18–44 the availability increases to about 97%. The daily use of the Internet has rapidly increased and among users aged 16–25 the percentage is currently 88% (World Internet Institute, 2010). The digital divide due to socio-economic factors still exists, but it is pronounced only in older users. For young people to have online opportunities, it is essential that they develop necessary digital skills or digital literacy (Sonck, Livingstone, Kuiper & De Haan, 2009) and it is important to have these opportunities at home (Jenkins, 2009). For today's children and the youth of tomorrow, whose parents are frequent Internet users, the Internet is and will be a part of everyday life and a natural arena.

A recent report from the World Internet Institute (2010) shows that youth differ from older people in how they use the Internet. Young people use it for amusement to a higher degree, while the practical use, like searching for information, is shared between the age groups. Health-related searches in general are common, specifically searches for knowledge about different health problems. According to Ybarra and Suman (2006), it was slightly more common to search for a close other's health condition than for the own. Ybarra and Suman's (2006) study also showed that people who search for information about a beloved one's health condition are more prone to seek social support. This may indicate that many health information seekers also are caregivers (Renahy, Parizot & Chauvin, 2010; Ybarra & Suman, 2006). Overall, Ybarra and Suman (2006) found a positive connection between gathering health information on the Internet and motives to seek help from health care providers. It therefore appears that health information seeking is used as a springboard, not preventing the user from seeking help but preparing them to take the next step.

As a group, young people supporting close others are therefore particularly appealing as target users with regard to health information seeking; as they

are young they are especially prone to use the Internet and as they are carers they may be especially prone to search for health information and seek social support.

Young carers

The intended users of the WBSS studied, as well as the young people participating in the studies of this dissertation, are called “young carers” or “young caregivers” in the research literature. “Young carer” as a concept was coined in a British research context and usually refers to young people <18 years of age carrying a substantial care burden within their family, due to a family member’s or several family members’ health conditions (Becker, 2007). It is hard to estimate how many children are affected and to what degree. Based on the young carer definition above, a rough estimate, with cross-national validity, of children in informal caring roles is around 2–4% of a particular age group (Becker, 2007). However, disregarding the young carer definition and talking in general terms about children who are close to a parent with some kind of addiction or physical or mental illness, this proportion will multiply several times. The definition may also vary with age (Pakenham, Chiu, Bursnall, Cannon & Okochi, 2006) and criticism has been raised about the limitation of the definition, which may exclude many young people affected by illness in the family (Newman, 2002).

In the present studies the definition has been extended in age and with regard to the supported person(s), to include: young people aged 16–25 who are close to and supporting someone with mental illness, be it a family member, or a relative, friend or girlfriend/boyfriend. Such an extended definition may be criticized for being too broad, and for including youth who could be defined as adults and also youth who would not normally be defined as carers. However, the extended definition can be justified. Firstly, the age limit of 18 is constructed and possibly an indicator of adulthood not fitting today’s industrialized societies (Arnett, 2007). Arnett reports that adolescence today may be prolonged because of different factors. Moreover, society demands higher qualifications for entering the labour market, which means longer education, which in turn can make this prolonged period in life an essential phase to be completed before being able to step into adult life. Secondly, recent research (Ali, Ahlström, Krevers, Skärsäter, 2012) shows that friends’ mental illnesses may have a considerable impact on young people, which justifies inclusion also of young carers supporting close others who are not family members.

It is not unusual for studies of young carers that the diseases of the persons cared for are mixed, so that young carers of persons with physical diseases

appear in the same studies as young carers of persons with psychiatric diseases. Dearden and Becker (2004) in a large national survey including 6,178 respondents reported that young carers of parents with mental illness were likely to provide more emotional care and less general (e.g. giving medication, helping with mobility, etc) and intimate care compared with young carers of parents with physical illness. However, other care tasks were reported to be quite similar in extent, such as domestic tasks and care for siblings. Aldridge (2002) also mentioned emotional care as specific for this group of young carers and highlighted the worry for the parents' short and long-term wellbeing, as a source of lack of concentration and decreased school performance. Ali et al. (2012) describe in detail what constitutes emotional caring by young carers of persons with mental illness.

For the entire group of young carers, their often heavy care burden has direct consequences for their wellbeing, including emotional isolation, carrying too much responsibility, and restricted opportunities to have leisure time, to pursue an interest or to meet with friends (Butler & Astbury, 2005). They may as a consequence have difficulties concerning education, work and participation in social life, which in turn affects their transition to adult life (Dearden & Becker, 2000). Young carers have been described as "invisible", "unseen" and "forgotten". It is known that young carers may be reluctant to tell about their situation, owing to emotions such as fear of being separated from their parent/parents, stigmatization, own shame or parents' desire to keep the situation secret (Becker, 1995; Banks, Cogan & Riddell, 2002; Thomas, Stainton, Jackson, Cheung, Doubtfire & Webb, 2003). However, the core reason for their "invisibility" is social neglect. A cross-national report (Becker, 1995) concludes that this, in fact, is the case regardless of type of social system. Ever since Becker's report, there has been a growing awareness of these children or young people and support initiatives and a considerable amount of research have emerged, not least in the UK. In Sweden, too, the support initiatives are growing (Nationell psykiatrisamordning och Socialstyrelsen, 2007) and in 2010 the Swedish Health and Medical Services Act (SFS, 1982) was amended, to ensure that these children's needs for support, information and guidance are met.

The impact of informal care giving in general is well documented, regarding both psychological effects and physical effects (Pinquart & Sörenssen, 2003; Schultz & Sherwood, 2008). The largest difference between caregivers and non-caregivers is to be found in measures of depression, anxiety and self-efficacy (Pinquart & Sörenssen, 2003). In the whole group of carers, age is positively associated with poorer health, while socio-economic status and social support are negatively associated with poorer health (Schultz & Sherwood, 2008). Pakenham et al. (2006) report a higher degree of somatization and a lower degree of life satisfaction in a group of young carers

compared with non-carers. Consequently, there is a strong incitement to support young carers.

Becker (1995) proposes that any intervention directed at young carers must be grounded in their *own stated* needs. While research on young carers' life experience and life context is plentiful there are few attempts to present support needs in a more aggregated form. Becker (ibid.) reports, based on interviews, that the most mentioned need of young carers (≤ 18 years of age) is to have "someone to talk to". Other expressed needs were: to be friends with someone who understands their circumstances, and for someone to empathize with and represent them without threatening interventions, information and advice on their day-to-day life. Cooklin (2006) presents a list extrapolated from a 5-year family support project involving young carers aged 4–16 years. In brief, his list includes the following needs: to acquire knowledge about their parents' illness, to have an adult to advocate for them, to have the opportunity to meet other young people living under similar conditions, to be listened to and taken into account, to help to understand mental health services, to get support with education and employment, and to acquire knowledge about what to accept/not accept in relation to the ill parent and when to seek help. Becker and Becker's (2008) report summarizes needs expressed by young carers (16–24 years of age) participating in interviews. These include: more support from the outside, opportunities to socialize with other young carers, advice and information about different practical things related to the ill person as well as to their own education, breaks from caring, individualized support, assessment of their own needs, and counselling by telephone or online.

These more comprehensive reports of young carers' needs show similarities in needs, but they differ in the age groups studied and in the illness of the supported person, with some having different illnesses (Becker, 1995; Becker & Becker, 2008) and others having only mental illness (Cooklin, 2006).

While the possibilities for young carers to obtain support are growing, it is unlikely that everyone can be reached. Although a WBSS would have the potential to reach a great number of young people very little is known about the possibilities to support young carers via technology (Grey, Robinson and Seddon, 2007). One of the very first studies dealing with a WBSS directed at young carers in the Netherlands was recently published (Drost, Cuijpers & Schippers, 2011), but the study mainly focuses on the development of the website. However, use of WBSSs for other groups of young people e.g. with specific diseases has been researched and online support has been developed for several groups including young carers.

Online support and its components

Barak and Grohol (2011) identify five types of current online support related to mental health: (1) *online support groups and blogs*; (2) *psycho-educational websites*; (3) *online counselling and psychotherapy*; (4) *interactive self-guided interventions*; and (5) *other types of online interventions*. The third type refers to common psychotherapy through technology, e.g. video support. The fourth type is what we mostly recognize as Internet-based cognitive behavioural therapy (CBT). The fifth type refers to mobile “apps” and interventions through virtual reality (e.g. Second Life). A combination of the first and second type is in focus in this dissertation, a combination used to support both mental and physical health conditions. It is a common combination when we talk about WBSSs and there are numerous examples, like kuling.nu, kankerspoken.nl, netdokter.se, slutta.no, reachout.com, diabit.se, youngcarers.net, youthhealthtalk.org and drugsmart.se, while many of those directed at young people have emerged in recent years.

Knowledge acquisition

Knowledge in a general sense helps us to better understand, grasp and manage the world in which we live. To know things can make us change our views and actions. Providing knowledge in health-related contexts is seen as a way to get better compliance or cooperation in treatment, and foster self-management, but also as a means to empower citizens (Ybarra & Suman, 2006). The extensive search for health-related issues on the Internet shows that such knowledge is viewed as essential among Internet users. Educational programmes for people with different diseases are common. In a review by Coster and Norman (2009), programmes for asthma were found to have clear benefits, while programmes for diabetes, depression and other chronic diseases were labelled “promising”. A review by Stoltz, Skärsäter and Willman (2009) on computer-based educational programs for people suffering from severe mental illness found no decisive evidence of effectiveness. However, according to the authors, studies must use more sophisticated designs to ensure statistical power and quality in outcome measures to be able to guide practice. In the field of psychiatry, different types of educational methods are common, e.g. CBT treatments with an important educational element, the method of “early warning symptoms” in bipolar disease, and the Beardslee method (Beardslee, Gladstone, Wright &

Cooper, 2003) and its derivatives where children acquire knowledge about their parents' illness (Reupert & Maybery, 2010). Also, psychodynamic therapy has a knowledge-oriented part, although its main focus is on the emotional understanding of oneself and one's own actions. Providing family carers with knowledge about their mentally ill family member is also viewed as an important way to cope with their situation (Picket-Schenk, Lippincott, Bennett & Steigman, 2008; Dahlqvist-Jönsson, Wijk, Danielson & Skärsäter, 2011). Knowledge has been highlighted as a significant factor for children with mentally ill parents to manage their situation (Cooklin, 2006) and it is also sought by young carers (Becker & Becker, 2008).

It is not known which components of successful educational programmes are effective (Coster & Norman, 2009). Understanding a disease may be important, but so is also how knowledge is mediated. The user's feeling of self-efficacy (Bandura, 1977) has been touted as essential with regard to effectiveness of self-management interventions (Lorig & Halsted, 2003). Self-efficacy should be understood as a belief in the own capability to flexibly deal with a particular reality, which often contains ambiguous, unpredictable and stressful elements (Bandura, 1984). Some researchers highlight engagement and endorsement among those providing the intervention (Jordan & Osbourne, 2007) to enable the user's capacity to attend, sustain and benefit from such programmes. In all types of psychotherapy the relation between patient and therapist is crucial (Norcross & Wampold, 2011; Sandell, 2004) and it is also valid in Internet-based treatments, where some personal contact (often in the form of an e-mail) seems essential for a successful treatment (Andersson, Carlbring, Berger, Almlöv & Cuijpers, 2009). In this way, the significance of how knowledge is mediated touches the other crucial component of a WBSS, namely social support.

Social support

Cohen and McKay (1984, p. 253) give a broad definition of social support, defining it as the "mechanisms by which interpersonal relationships presumably buffer one against stressful environments". Social support may further be operationalized, as shown in the different studies in Reblin and Uchino's review (2008), as structural support (e.g. as part of a network or a system of networks) or as transactions between individuals (e.g. as emotional support). Social support has been shown to be a protective factor with regard to mortality (Berkman, 1995), mental health (Dalgard, Bjørk & Tambs, 1995) and physical health (Reblin & Uchino, 2008). Social support has also been reported to be positively associated with mental health among young adults (Bovier, Chamot & Perneger, 2004) and college students (Hefner &

Eisenberg, 2009). One study of young carers has shown social support to be a strong predictor of adjustment to the care situation, where adjustment was viewed in terms of the degree of absence of distress, positive emotions, life satisfaction and ability to benefit from the care situation (Pakenham, Chiu, Bursnall & Cannon, 2007).

The effect of social support has been referred to as a “buffering effect” against negative life events. In the study of Dalgard et al. (1995) the buffering effect is shown to be connected to the “locus of control” and only applied to people experiencing a lack of control over their lives. Subjects in this study who felt in control showed a low level of stress in spite of negative life events and poor social support. These findings seem to be supported by a later study by Bovier et al. (2004), in which individuals’ internal resources of mastery and self-esteem have been suggested to work as mediators of social support by strengthening these resources. Research overall shows a strong positive association between social support and health, but further research is needed to explain the cause of this association (Reblin & Uchino, 2008). Knowledge acquisition and social support may be favourably combined and offered in a WBSS.

Web-based support

Web-based support has been around since the 1990s, or possibly as early as the 1980s, according to Martha Ainsworth’s (1995) no longer updated website. An early study describes patients with acquired immunodeficiency syndrome (AIDS) who were provided with terminals in their homes (Brennan, Ripich & Moore, 1991). They received practical information, decision support and possibilities to communicate. Communication took place in the form of private e-mails and a bulletin board. The authors observed that the initial use was exclusively for social contact, while questions and exchange, following the realization that their disease was shared by others, emerged slowly. Feenberg, Licht, Kane, Moran and Smith (1996) describe an online journal and a bulletin board for amyotrophic lateral sclerosis (ALS). In their study, information and knowledge exchange was common, but there was also exchange of experiences and getting and giving social support. The authors foresaw a patient role in change and a “new kind of empowerment of patients” (Feenberg et al., 1996, p. 131). A study by Galegher, Sproull and Kiesler (1998) reported that at the time of their study, more than 200 Usenet groups or bulletin boards were devoted to poor health conditions. Their article outlines the specific settings in online support groups with regard to how people gain legitimacy and authority and how the positive handling of this reinforces community building, which in turn clarifies the acceptable discourse in the group.

A more recent study of people using four online forums (Kummervold et al., 2002) for mental health issues concluded that for the majority of users, anonymity was important and made it easier to disclose themselves. The absence of visual and social cues was suggested as a vital part in this process. The authors also found that online support was a complement to normal care, and that many participants wanted professionals to take a more active part in the forum boards.

There are also quite a few studies on the effect of online support. A review by Eysenbach, Powell, Englesakis, Rizo and Stern (2004) could not show convincing effects of online support, but on the other hand found no evidence of harmfulness. In studies where an effect was seen, the authors concluded that it was difficult to judge what was effective in the intervention, as provision of information and peer-to-peer support were often mixed. A later study (Freeman, Barker & Pistrang, 2008) compared two types of online support for students with psychological problems. One offered information only, the other in addition had an online support group. Both showed improvements in two outcome measures, but there were no significant differences between them. A review by Griffiths, Callear, Banfield and Tam (2009) on support for depression found some evidence that the users benefited from participating in an online support group. The authors called for studies that manipulate factors such as group size, presence/absence of moderator or level of moderator participation to evaluate the effect of these on outcome variables. They also found it notable that no study could be found that investigated online support specifically directed at adolescents, who may be a suitable target group. However, a recent study by Shandley, Austin, Klein and Kyrios (2010) evaluates an online game intended to enhance protective factors to mental illness among youth, with slightly positive results. Furthermore, a systematic review by Stinson, Wilson and Gill (2009) found that there is emerging evidence that self-management interventions delivered online can improve symptoms in certain physical diseases among children and adolescents. A general conclusion of the above studies could be that there is an uncertain but probable benefit from online support systems or WBSSs. However, Barak, Boniel-Nissim and Suler (2008) argue that traditionally used outcome measures like symptom reduction may not be relevant for use in connection with web-based *support* interventions. They argue that such online support is more prone to have general effects, like increased feelings of empowerment, and not specific effects that might be expected in *treatments* (e.g. Internet-delivered CBT). In their review and meta-analysis, Barak, Hen, Boniel-Nissim and Shapira (2009) report that online treatment dominated by CBT is as effective as face-to-face therapy; however, that it is more effective with anxiety problems than with other types of problems.

Willingness to use WBSSs may also be questioned. In a study by Van Uden-Kraan et al. (2011), 679 adults with breast cancer, arthritis or fibromyalgia were asked about their use of face-to-face and online peer support. Only a minority had engaged in such support: 10% in face-to-face support and 4% in online support. Similar results were presented in a Californian population study (Owen, Goldstein, Lee, Breen & Rowland, 2010) including 6,795 persons with mental as well as physical chronic health problems: 16% had engaged in face-to-face support and 1.8% in online support. When asked, the respondents preferred face-to-face support to online support. It seems that young people with poor mental health are more inclined to use online support (Gould, Munfakh, Lubell, Kleinman & Parker, 2002; Van Uden-Kraan et al., 2011; Owen et al., 2010), but perhaps not without doubts. Gould et al. (2002) studying 519 adolescents (13–19 years of age) found that considerably more of them made use of personal support from friends or parents than of Internet support, 80–90% compared with 18%. A study by Horgan and Sweeney (2010) investigating use of Internet for information and support on mental illness in 922 young students (18–24 years of age) reports that about 80% preferred personal support (doctor, parents, relatives, friends) to Internet support. Becker and Becker's (2008) report on the attitudes of young carers (16–24 years of age) to online support likewise suggests that face-to-face support is preferred. However, Horgan and Sweeney's (2010) study showed that those young people who preferred Internet sources (20%) did so because of the possibilities of anonymity, privacy and confidentiality and because of the ability to get support without having the feeling of being judged. A conclusion of these results may be that Internet-based support in general suits a limited group, often young people with mental health problems. There are also indications that their reason for choosing to use online support is secondary rather than primary, possibly supported by the benefits of anonymity offered in online support.

Not enough is known about how or for whom online support works. Stinson et al. (2009) propose that we need to develop theories about Internet interventions to increase our understanding of how these interventions work and how they differ from traditional methods. To increase understanding, studies of development processes of such support systems may be essential, especially if the users are directly involved. The users' specific knowledge may have the potential to inform the design in unexpected ways, thus adding knowledge about crucial elements, which in turn can inform an overarching understanding of such a system. However, to make use of such knowledge it may also be necessary to critically scrutinize the design process and the opportunities users have to influence design. Power relations in design settings (Light, 2010; Holland, Renold, Ross & Hillman, 2010), the impact of designers' approaches (Markussen, 1996; DiSalvo, Maki & Martin, 2007;

Steen, 2011) and the different social conditions of users and designers (Markussen, 1996) may have an influence on the process. However, besides the challenge of user influence there are other aspects of design to consider, which influence how design is viewed.

Perspectives on design

One of the most cited books on design is Simon's (1996) *The Sciences of the Artificial* published in its first edition in 1969, in which he wants to give design the status of science. Simon argues that design is a truly transboundary activity, to be found in the engineer's design of an engine as well as in the doctor's setting up of a treatment programme or in the architect's planning of urban environments. Simon found it ironic that this type of professional activity was less and less acknowledged in the natural sciences up to about the mid-1970s, when there was an emerging interest for design itself as a science, a "science of the artificial". Simon thus separates the natural sciences, studying how natural things are and work, from the science of the artificial, describing how to make artefacts with desired proportions, fulfilling certain needs and meeting specific environmental demands. For Simon, the design process resembles an optimization process which in principle is computable. However, because of a large number of unforeseeable factors, in practice the design process is a search for a satisfactory solution, a "satisficing process" to use a word coined by Simon (1996). Such a solution is just one of many possible solutions and the concept of *design space* is commonly used to encompass all possible solutions to a design problem, given that each solution meets certain demands (Westerlund, 2005; Sluis-Thiescheffer, 2007; Bratteteig & Wagner, 2010).

According to Simon (1996), the way to finding a satisfactory solution is through a generate-test cycle. This means that design ideas are tried out against desired proportions and environmental demands until a "satisfactory fit" situation emerges. Hevner, March, Park and Ram (2004) use the concept of a *build-evaluate loop* to describe the same process. They view the process and the product as two parts of the design process: *process* aims at the activities (assumed to be creative) producing the artefact, while *product* aims at the feedback that is gained in evaluating the artefact, in turn used to improve both process and product.

Unsurprisingly, there are several views on the design process. Dorst and Dijkhuis (1995) distinguished two main paradigms in the discussion on design, one of which the authors assign to Simon. His is the rational problem-solving process or optimization ("satisficing") process described above. Dorst and Dijkhuis (ibid.) assign the other paradigm to Schön (1992), whose

proposal on design as reflection in action was a reaction to the rational problem-solving process. Schön viewed design as a reflective conversation, where the designer actively frames the unique problem and makes moves based on what he or she sees (ibid.). Fallman (2003) in his overview distinguished three ways to describe design: the conservative, the romantic and the pragmatic account of design. The *conservative account* resembles a mathematical process, where designers follow a stepwise process. An identified problem is analysed, and solutions to each part of the problem are developed. The part solutions are put together to constitute a design solution to the whole problem. The *romantic account* is based on the individual designer and his or her special characteristics and skills. The process is guided by his or her values and taste. It is the process of a genius making art in a non-transparent process. Finally, in the *pragmatic account*, design could be described as a hermeneutic process where designers are involved in a situated and reflective dialogue. There is no clear problem to be analysed; rather, the problem is unstructured and has to be defined during the process. The three accounts all seem to follow the latest contemporary views in psychology and the educational sciences and could by turns be viewed as belonging to information-processing theory, constructivism and the socio-cultural tradition (cf. Koschmann, 1996).

In some design research domains the concept of *process* is utilized in connection with the conservative account only, describing something instrumental or detached from people's actions or interaction (Fallman, 2003) encompassing a linear, specified top-down schedule. However, researchers also use the notion of process, while still acknowledging deviations and unplanned actions. Guindon (1990) observed that opportunistic ways to handle a design problem were common among designers and also functional, as design problems are often ill structured or "wicked", a term introduced by Horst Rittel in 1969 (see Rith & Dubberly, 2006). Dorst and Cross (2001) suggested that designers work with the problem and the solution at the same time while looking for "surprises", i.e. unexpected ways to frame the problem. When comparing the three different perspectives on design it is obvious that the object of study in the socio-cultural tradition would neither be a rational optimization process nor the individual designer's characteristics. The object of study would, rather, be human actions and interactions with other humans, designers as well as users, as well as with the designed artefact and other surrounding artefacts. Thus, design studies that explore what people do and how they interact are clearly close to sociology, psychology and/or the educational sciences. Although the phenomenon of study can be labelled "artificial", it is at the same time no more than a study of human interactions in a specific setting. In such a perspective we cannot view processes as instrumental and programmatic. Therefore, when the

concepts of *process* or *design process* are used in this dissertation, they are intended to comprise human actions and interaction as their essential parts.

Design as a social process

In contrast to the view of design as a rational problem-solving process, Bucciarelli (1988) introduced design as a social process. In his study he approached design using an ethnographic methodology to view design “as it is” (1988, p. 160). He studied two design engineering firms producing technical artefacts and demonstrated how different expertise and levels in and outside the firm were involved in the design process. He argued that design goes beyond artefacts and expertise, involving a process where these ingredients are “wielded and realized, negotiated and compromised” (p. 161) in a social process.

In their observations on social processes in design, Cross and Clayburn-Cross (1995) draw attention to activities such as: negotiation of roles, planning of activities, and gathering and sharing of information, as well as developing and adopting design concepts and avoiding or resolving conflicts. They found these activities to be significant parts of the design process interacting with other parts of the process.

Similar design activities have been described by others. Stempfle and Badke-Schaub (2002), for instance, developed a theory based on four basic cognitive operations: generation, exploration, comparison and selection. These, according to the authors, are connected to two main focuses of activities they distinguished in design teams (DTs): *content*, activities directed to the design task, and *process*, activities directed to the structuring and organization of the group process. Stempfle and Badke-Schaub (2002) used the model to explore design activities in three different teams. When investigating communicative acts they found that regardless of a team’s total communicative acts the relationship between process and content was 1 to 3, i.e. one-third of a group’s communication aims at structuring the group process. Similar results have been reported by Fisch (according to Stempfle & Badke-Schaub, 2002) when describing non-design groups. Robinson (2012) performed a study in which design engineers hourly entered data on their current work task. He concluded that social collaborative work occupied about 40% of their time, while technical work occupied about 60%. His results do, however, suggest an overlap between the two, i.e. they are not entirely two separate things. What designers do in DTs has been further refined with different methods. Peeters, Van Tuijl, Reymen and Rutte in 2007 developed a design self-reported behaviour questionnaire and, using factor analysis, identified twelve design behaviours which could be grouped into three categories: design planning, design creation and design cooperation. Recent research such as the

study by Matthews and Heinemann (2012) has used conversational analysis to uncover in greater detail what happens in interaction critical to the design outcome, e.g. how arguments for different solutions are presented in an indirect way, supported by claims about how the intended target group work.

Group processes in design teams

What designers do can also be viewed in the light of general group processes. Tuckman (1965) reviewed research that described group processes and different kinds of team work in small groups. Based on his study he discerned two realms of functioning in groups: the interpersonal realm and the task-activity realm, which well correspond to those identified by Stempfle and Badke-Schaub (2002). In his review he found correspondence in development over time between these realms, which he divided into the well-known stages of forming, storming, norming and performing. Tuckman and Jensen (1977) have proposed an additional stage, adjourning, to reflect additional research. Although well known and frequently used, Tuckman's stages have also been criticized (Poole, 1983) for not acknowledging the complexity of group development.

Gersick (1988) developed another interesting model, based on work teams with a clear time limit. While studying the complete lifespan of eight naturally occurring teams, Gersick observed that these groups did not progress through the stages proposed by Tuckman. She found that the groups used a wide range of behaviours in doing their work. However, the timing when they changed their way of working was highly concordant. She found that the groups changed their focus halfway through the project time, at which point they redefined their goals and entered a "period of momentum" characterized by execution and progression. According to Gersick, the primary driving force behind this redefinition of goals was the team members' awareness of limited time and deadlines. Her theory is thereby of special interest with regard to DTs.

Similarly, Curtis, Walz and Elam (1990) observed a change in software DTs' degree of agreement halfway into the design process. The agreement between the members of the DT increased until halfway through the process, after which it decreased. The authors' explanation for this shift was that the DTs' awareness of time limits forced a consensus at too early a time point, leaving underlying disagreements unresolved. Passing the halfway mark of the process, such disagreements increasingly came to the surface again, resulting in the decrease in agreement. This observation links to Gersick's results and underscores the impact that productivity goals may have on the design process. There have been attempts to combine stage theories (e.g. Tuckman, 1965; Tuckman & Jensen, 1977) with Gersick's model (1988). According to

Chang, Bordia and Duck (2003), both models are valid but focus on different entities. Chang et al. (ibid.) refer to the “perform” stage (in stage theory terminology) as coinciding with the “period of momentum”. In a later study, Dennis, Garfield and Reinicke (2008) suggested that the reason for the difference between the models could be traced to the development in the first half of a group’s life. When group members earlier have developed a common understanding as to how to view and perform a task their development will resemble Gersick’s model and they will quickly engage in the task. However, without having developed this common understanding the group will go through the stated stages to find that common understanding. One circumstance that might stand in the way of a common understanding is today’s distributed environments.

Distributed design environments

In line with the omnipresent availability of Internet connectivity and the need to engage different expertise in design projects, distributed design environments have become more common (Fiore, Salas, Cuevas & Bowers, 2003; Larsson, 2003). In their review, Ebrahim, Ahmed and Taha (2009) conclude that core characteristics of distributed or virtual teams are: a small and temporary group, geographically distributed; and coordination through electronic information or communication technologies. Possibly, these characteristics will affect how different members in DTs understand their task and work together. Rocco (1998) explored group communication both face to face and through e-mail. Six groups were expected to discuss and try to come up with solutions to a social dilemma, a situation where solutions that were optimal for the individual became suboptimal for the collective. She showed that face to face, the studied groups were able to cooperate early and find an optimal solution. Groups communicating by e-mail, on the other hand, never reached a state of cooperation, and communication was highly individual. However, they generated and explored more solutions (though never in agreement). Finally, Rocco (ibid.) showed that a face to face pre-meeting with an e-mail group changed their pattern of cooperation to come very close to the face to face condition. She identified trust to be a crucial factor in these processes. Fiore et al. (2003) stated that distributed environments have a significant impact on the team members’ work and suggested that “team opacity” is a central factor in distributed team work, by which is meant a decreased number of cues in such a setting compared with a collocated setting. Larsson (2003) argued that true collaboration implies that team members actually think together and do not just exchange information and opinions. Larsson (ibid.) studied a global team during occasional collocated meetings and noted that during those meetings they used any available way to communicate. When language was not enough they used gestures,

storytelling, sketches and all possible objects to visualize and describe. Larsson (ibid.) stressed the interactional and situational characteristics of design collaboration and suggested virtual shared objects as a complement to more common shared media such as video, audio, shared screens, and so on. Maher, Bilda and Gül's (2006) study explored different ways to communicate in virtual design environments, e.g. by face-to-face sketching, remote sketching and using 3D virtual world technology. They concluded that the different ways to communicate seemed to focus the designers on different aspects of the design process. Hence, they, like Larsson, suggested that ideally multiple ways to communicate and represent a design task should be supported. In Ebrahim et al.'s (2009) review the advantages of virtual teams could be summarized as follows: cost- and time-effective development, the possibility to tailor the team, flexibility in terms of time and place, optimized and more creative individual contributions, and the fact that the process is more task-oriented. Disadvantages could be summarized as vulnerability to mistrust and conflicts, a decreased conceptual understanding and monitoring of activities, and the fact that many project managers are challenged by geographical dislocation. Some of Ebrahim et al.'s (ibid.) conclusions coincide with Rocco's (1998) findings of higher individual creativity and the problem of building trust in groups using e-mail communication only. Moreover, some of the disadvantages seem to be paralleled with the solutions suggested by Larsson (2003) and Maher et al. (2006).

Involvement of users

The hitherto mentioned studies about design from the perspectives of social processes, general group processes and distributed environments have excluded users as partners in the design process. Gould and Lewis' (1985) article is often mentioned as a starting point when considering user influence in software design in general. They state three principles for software system design: early and continuous focus on users, empirical measurements of use, and iterative design. The results of a survey led them to conclude that although many designers find the principles obvious, they are rarely recommended or followed in practice. Gould and Lewis (1985) give a range of explanations as to why designers are reluctant to involve users, including under- or overestimation of users' diversity, a belief that users do not know what they need, the belief that there is no need of user involvement since a rational process is followed, and a prolonged design process. Ever since their article, many articles have discussed the issue. Saarinen and Sääksjärvi (1990) stressed the quality as opposed to the quantity of user involvement. They also advocated a balance between participation of users and system analyst competence instead of just relying on "the magic power of participation" (p. 38). Lee and King (1991) likewise highlighted quality of

user involvement and reported that a fit between users' desired participation and their actual participation contributes more consistently to user satisfaction. Grudin (1993) argued that structural and organizational constraints in companies disfavour user involvement and listed several problems connected to these constraints. In essence the point is that in many organizations there is no real place for user participants. In a review, Kujala (2003) reported that user involvement generally had positive effects on user satisfaction and that user input to capture requirements was effective. Only one study reported negative effects on "system success" (p. 10).

Darses and Wolff (2006) studied the design of a partly human-operated machine. The project steering group regularly met with the users/operators and passed information from these meetings on to the designers. The authors concluded that the designers in their work often viewed users as a kind of sub-system of the machine, thus informing how users' needs and views were perceived.

What about use in practice? A survey by Vredenburg, Mao, Smith and Carey (2002) concluded that user involvement was widely acknowledged but seldom used and that cost-benefit trade-offs are the most common consideration. Participatory design was about the least used method, while informal expert review was used most. A recent survey (Majid, Noor, Wan Adnan & Mansor, 2010) among software practitioners showed that users were mostly involved before and after the design process but rarely when e.g. a user interface is being developed. The authors suggested that users should be involved in the entire process.

The general impression is that involvement of users in design is beneficial for the outcome, but still, in practice user involvement is not prioritized. Cajander (2010) describes a similar picture of the situation today, where a culture of rationality and efficiency in companies may be an obstacle to user influence, i.e. reaching about the same conclusion as Grudin (1993). The picture today more or less seems to resemble that described by Gould and Lewis in 1985. In cases where users really are involved there may be different degrees of involvement and different goals with involvement. One of the more far-reaching ways to involve users is participatory design.

Participatory design

According to Sanoff (2007), historically there are two main traditions in PD: (1) an Anglo-American tradition, developed in the 1960s with the aim to let citizens engage in community building and thereby increase community consciousness, and give all citizens the possibility to have an impact on

development, planning and financing; and (2) a Scandinavian tradition, linked to labour unions fighting for influence during a time of technological change. The latter was based on a Marxist view and assumed a need to address the unequal workplace power relations that result from the conflict between capital and labour (Törpel, 2005; Spinuzzi, 2002). Designers engaged in collective and collaborative design to help workers gain an influence over how new computer-based tools were developed and shaped. This cooperation started in the 1970s between Kristen Nygaard and the Norwegian Metal Workers' Union and was based on a commitment to industrial democracy (Ehn, 1988). In the UTOPIA project, where Pelle Ehn collaborated with graphical workers on a newspaper, there was a shift from an earlier focus on education about technology to a focus on developing ways for workers to discuss and explore new technology (Spinuzzi, 2002). The use of mock-ups in this process was essential and the aim was that technology, while automatizing some work, would use but not drain the workers' experiences and skills (*ibid.*). This way of working with design towards empowerment and democracy was called the "Collective Resource Approach (CRA)". This approach rejected traditional system descriptions and viewed the handling of technology as a process where resources and knowledge were collectively built together with the designers (Bødker, 1996, citing Munk-Madsen).

Typically, a PD process has three phases (Spinuzzi, 2005): an initial exploration of work in which the designers familiarize themselves with different aspects of work; a discovery process where the designers and users try to understand work organization and envision and clarify future goals; and finally, prototyping, where the users and designers iteratively realize artefacts fitting the goals. Spinuzzi (*ibid.*) also lists three essential ingredients of PD: to increase workers' quality of life – a democratic and functional empowerment, to engage in a continuous collaborative development, and to follow an iterative process.

The Scandinavian tradition of PD has many different approaches, which Törpel (2005) broadly divides into comprehensive and non-comprehensive approaches. In the latter type of approach, PD is not the main focus, although it still contributes to research and practice, e.g. by developing new concepts or methods (*ibid.*). Participatory design has ever since its development been particularly frequently used in work-related contexts including the health care context, e.g. in development of computer support for teamwork in primary care (Sjöberg & Timpka, 1998) or telemedicine systems for emergency care (Li, Wilson, Stapleton & Cregan, 2006). Workplace environments are characterized by relative stability. They usually exist over extended time periods, where the persons working there learn to know the workplace and

each other. Theoretically such environments could be described as communities of practice.

Communities of practice

The concept of *communities of practice* was coined by Lave and Wenger (1991) and elaborated by Wenger (1998) to a complex theory of learning in social practices. Such practices exist at work, at home and in school, as well as elsewhere. As a theory of learning the concept has also been applied to understand the design process in similar settings. Wenger's theory was influenced by several theoretical movements, and although Vygotsky's (1978) work is not central to Wenger their views on the meaning of artefacts in human life are very close. A basic idea in Vygotsky's work, further developed by Leontiev (Kaptelinin & Nardi, 2006), is that humans seldom relate to the world directly. Rather, they relate to it through tools, which mediate activities. Tools can be physical, such as hammers, but also semiotic, such as maps (ibid.). Another basic idea is that mind and society are not separated. Individuals appropriate culture and develop their own meanings based on those already there. This relationship between society and the individual is open for dynamic exchange in every moment (ibid.). At the same time, as artefacts are resources to do things with or to think with, they are also carriers of the culture, and affect how we do things and relate to the world. Others, e.g. Säljö (2006), have further developed the concept of *cultural tools*. In Wenger's theory of communities of practice (1998) the term *reification* is used. Reification has the same function of carrying culture, the community's culture. Reification is an abstraction and projection of an experienced meaning or, in a community of practice, a negotiated meaning. Thus, reification mirrors an aspect of the practice. Its complementary part in a practice is participation, for example when a medical congress tries to agree on a diagnostic criterion. Wenger stressed that reification, e.g. a set of rules, cannot fully capture such an experienced meaning and consequently it may be insensitive to the contexts in which it is used. Reification as such can both expand and restrict thoughts and actions. At the same time as it focuses an effect and is a "portable meaning" it may also become a substitute for the understanding of what it really stands for. A set of rules used to simplify complex actions might for instance become "the truth" and the background to these rules is forgotten or never thought of. The term is close to that of tool or cultural tool, artefacts to support our thinking and actions in the world.

A community of practice is characterized by its members' mutual engagement, shared repertoire and joint enterprise. The community of practice in a workplace context is not equal to the official workplace, but goes beyond, for example by including the normally invisible and not

reflected on ways of performing work tasks in the common endeavour. It consists of its members' interrelations and actions to strive for the joint enterprise. The shared repertoire assumes a history where the How To Do Things has been developed over time. Using this framework to understand a PD process assumes two communities of practice, the designers' and the users'. Hence, PD can be viewed as a process taking place where the two communities of practice overlap each other (Bødker & Iversen, 2002; Ehn, 2008). The members become so-called *legitimate peripheral participants* in each other's community of practice. The role of a legitimate peripheral participant comprises a gradual learning of and introduction to the life of the community of practice through observation and apprenticeship. By this participation the legitimate peripheral participant obtains not only formal knowledge but, through learning in the context of the community of practice, also tacit knowledge, i.e. *knowledge by doing*, which is one characteristic of PD (Spinuzzi, 2005). Nardi and Engeström (1999) outline nicely what such invisible work might be. Thus, in a designer-user (co-designer) relationship the designer becomes the apprentice in the user's world, and vice versa. The design object could be viewed as a so-called *boundary object* (Star & Griesemer, 1989; Wenger, 1998) binding these two communities of practice together. A boundary object can be understood as an object that is adaptable to different social worlds, while at the same time offering a stable identity across them (Star & Griesemer, 1989) or being a reification that bridges two practices (Wenger, 1998). Thus, the design object encompasses the learning process between the worlds of the users and the designers. The process is complex as the object that is designed also is used as tool or resource to think with about the emerging design object, if applying Vygotsky's model (1978). Thus, such a process includes transactions between the inner and outer, the individual and the social world.

Well and less well structured contexts

If the context of the design work is a workplace, as in the UTOPIA project, the object of design would also be used in the very same context. Apart from natural obstacles in the process, it may be assumed that the incitements for collaboration will be high. The described contexts of communities of practice can be viewed as well structured, with strong links between their members.

However, all arenas for design are not that well structured. Examples are the arena of designing with psychiatric inpatients (Crabtree et al., 2003), homeless people (Le Dantec et al., 2010), young carers and in other environments where individuals are more loosely connected or dispersed. In these cases no common practices have been developed and no common history exists. Participatory design has also been adopted in such less well

structured contexts, but this raises the question as to what view on design is to be taken in these cases. Bergvall-Kåreborn and Ståhlborst (2008) describe conflicting views in the PD community today where one side regrettably observes a drift away from the political stance of PD, while the other wants PD to adopt contemporary trends, like distributed development environments. One such contemporary discussion points to the challenge of PD in contexts where no community exists and where consensus is beyond reach (Ehn, 2008). Here Dewey's (1991[1927]) concept of *public* may prove to be an interesting companion to contemporary PD.

Dewey's concept of public

There are two important reasons as to why Dewey's (ibid.) concept of *public* is suggested as a possible way of dealing with the mentioned challenge. Firstly, in contrast to the stable communities of practice, publics are temporary, emerging when they are needed and then disappearing. Secondly, while communities of practice are based on their members' mutual engagement, shared repertoire and joint enterprise, publics are based on a specific social condition to which a group of people have reacted. Thus, publics are not driven by "new goals", but rather, by *handling a particular problem*.

The concept of *public* was introduced by John Dewey in his book *The Public and its Problems* (Dewey, 1991[1927]), which describes the author's search for the state, and how the state emerges. Dewey's argument is that people relate to each other and that their actions sometimes have indirect consequences which must be taken care of. One example: a new road is constructed. An indirect consequence is that people living close to it come to suffer from headache due to excessive noise. According to Dewey, such a group of people, who are indirectly exposed to the result of somebody else's action, find themselves placed in a certain "social condition". What they are exposed to may be good or bad or both good and bad, the idea being that people take action to preserve the good and to regulate or stop the bad, by forming a "public". The public is characterized by assembling around a specific issue and by letting "officials" represent them when dealing with the controversy surrounding the issue.

Dewey (ibid.) pointed out that communication about the social conditions and its consequences is a prerequisite for a public to emerge, as is intellectual and emotional appreciation of the social conditions. Dewey uses several terms for emerging publics, including the term "generated" which suggests that publics can be viewed as constructed, a view of specific interest to designers. If a public can be constructed, this process could be supported through designed artefacts. The idea of constructed publics has been further

outlined by DiSalvo (2009) who proposes that artefacts aimed to support the emergence of a public should facilitate collective awareness of the issue in all its aspects: the source of actions, the indirect consequences and the anticipated future consequence of these actions (ibid.).

The meaning of issues has also been investigated. Marres (2007, p. 775) uses the concept *attachment* which relates to human attachments in non-human things like music and politics, and proposes that issues are the entangled attachments of the public actors. Therefore, these attachments are the source of public involvement in controversy. To supplement Marres' (2007) analysis one may also draw from an observation from social identity theory (SIT), stating that very little is needed to make a group of people feel distinguished from other groups and committed to the own group (Tajfel, 1982), thus making possible the entanglement of individual attachments.

Although there are quite a number of studies of design for the public or design in public places (See Chang, Jungnickel, Orloff & Shklovski, 2005; Paulos & Jenkins, 2005), studies involving construction of publics are sparser. Studies by DiSalvo et al.(2007) and DiSalvo, Lodato, Fries, Schechter and Barnwell (2011) explore how artefacts can assemble a public around a specific issue. Le Dantec et al. (2010), in turn, have used the concept of *publics* as a tool in the design process of a support system connecting care providers with homeless people. A design process in that context must be viewed differently from a design process taking place between two communities of practice. It is not a mutual learning process where users and designers aim to participate in each other's language games or become legitimate peripheral participants in each other's communities of practice. Rather, the process must be viewed as temporary meetings between publics, willing to engage and cooperate in handling a current problem.

In contrast to work-related settings, the use of PD in similar sensitive and at the same time distributed settings calls for additional methodological reflections. Consider the case of young carers. The amount of time that users find reasonable to allocate to a research project may be limited, given other occupations like studying, supporting friends or parents and having leisure time. Furthermore, the users in such a setting will meet during the design time and then dissolve. These conditions may from a classical PD perspective be expected to negatively affect the experience of being involved, thus counteracting basic ideas of PD. However, the design process between publics may be understood as a problem-solving activity from different points of departure. In the process of developing an artefact a mutual understanding of that artefact can be supposed to emerge during the dialogue around the used mock-ups, virtual mock-ups, sketches, etc (cf. Luck, 2007). This view does not point to less involvement, but rather, to another kind of

involvement, a temporary involvement in a current problem.

In the study by Le Dantec et al. (ibid.) the parties' contributions to the design were analysed as grounded in different publics with different social conditions. The constructed artefact in Le Dantec et al.'s study was designed with two interfaces or entrances as a result of the two publics' specific needs. However, there was a common challenge to handle – to give homeless people access to more appropriate information, like current availability of beds in shelters. Hence, a designed object as in the studies by DiSalvo and co-authors (2007; 2009; 2011) as well as a design project such as in Le Dantec et al.'s study (2010) can constitute the point that is able to assemble publics, by highlighting issues.

Given the basic conditions for a public to emerge it could be stated that the designed website would be a good tool to construct a public, since it offers possibilities to share thoughts, ideas and knowledge. Thus, it has the potential to ease communication about social conditions and their consequences and foster intellectual and emotional appreciation of social conditions. According to the social identity model of deindividuation effects (SIDE) (Reicher, Spears & Postmes, 1995), the relative anonymity of the Internet will not, as the classic deindividuation theory suggests, make us demoralized or lose control (Postmes, Spears & Lea, 1998). Rather, the anonymity will make our social identity more salient and as a consequence, Internet groups may more forcefully express their group identity (Postmes & Brunsting, 2002). Examples of such phenomena are Avaaz, a worldwide human rights group currently gathering of over 17 million people, and Missing People, voluntarily searching geographical areas to find missing people. Avaaz mostly use e-mail combined with a website, while Missing People use Facebook. When people use a designed object they also do something with it; they use the design in a special way. This fact has generated the fairly new research area called "Meta design".

Meta design

Meta design is an emerging conceptual framework in design that takes the meaning of participation yet another step further. Its emergence is based on the assumption that future use cannot be fully anticipated at the moment of design, therefore calling for design methods and design thinking that allow later re-design by the user himself (Fisher & Giaccardi, 2006). Redström (2008) discusses design in terms of "thing design" and "use design". Thing design corresponds to how things are intended to be used, i.e. what Simon (1996) termed the "purposefulness" of a designed object, while use design corresponds to how users really use the object. Redström (2008), who takes his starting point in user-centred design (UCD), envisions a spectrum of

approaches to design. At one end of the spectrum the traditional UCD is found, which aims to try out use before the real use. At the other end a very open approach is found where the intentions of use are not determined; rather, they are defined by the real users in an act Redström calls “design after design”. Fisher and Giaccardi (2006) points out that this view does not imply that designers transfer the responsibility of design to the users. Rather, the idea is to provide the user with opportunities to adapt or extend the system to his or her needs. However, at the design after design end of Redström’s spectrum it will be less clear who is the designer. This ambiguity corresponds to the frequently referred to trends in Internet use where consumers are said to become producers (Buckingham, 2010), e.g. in blogs and on YouTube, triggered by the emergence of the so-called “Web 2.0 paradigm” (O’Reilly, 2007) during the last decade. Related to a PD process of a WBSS the participation in design will be extended also to the real users and may be extended over the lifetime of the system. Web 2.0 technology would allow continuous influence in several ways, e.g. the possibility to express oneself and participate in discussions. Moreover, Wiki technology would allow users to also impact content. However, much content related to WBSSs should not be changed, e.g. medical descriptions and interviews with sufferers. Furthermore, the number of “producers” with regard to Wikis or forum boards is in general very low compared with all users (Nielsen, 2006). Therefore, the use of Web 2.0 technology to support design after design might turn out to be a democracy problem. For websites in general, a more reliable method to provide information for re-design is to use web page statistics (cf. Arendt & Wagner, 2010; Hasan, Morris & Proberts, 2009). With help of such statistics, both simple and more complex data can be extracted. Google analytics is a frequently used tool today able to calculate quite advanced measures. Apart from page views, time on page and similar statistics, it can also offer measures of visitors’ pathways through the website and compile customized reports. Of course web page statistics of use can only tell us what type of content out of the existing content users prefer and not what they would prefer in addition to the existing content. A strength, however, is that such data are only based on real use and not on views and opinions.

Research may also be viewed as a participatory process where new elements are added to a common design project. In essence, research would also belong to the domain of meta design, i.e. results are possible to rethink or re-interpret. This dissertation is a part of this participatory process and will hopefully contribute to fill some of the gaps in its research domain.

Gaps in current research

Very little research has been done on the use and design of WBSSs for young carers (Grey et al., 2007) and for the group of adolescents as a whole (Griffiths et al., 2009). Before the studies in this dissertation, one study (Drost et al., 2011) had explored the design of a WBSS for young carers, while some explored young people's views on other types of WBSSs (Stinson et al., 2008; Nordfeldt, Hanberger & Berterö, 2010; Giesbers, Verdonck-de Leeuw, Van Zuuren, Kleverlaan & Van der Linden, 2010). Studies engaging young people in a PD process are rare and mostly found in the field of games development (Danielsson & Wiberg, 2006; Mazzone, Read & Beale, 2008) and in the other tradition of PD, e.g. in community projects promoting youth health (Percy-Smith, 2007; Flicker et al., 2008). Moreover, existing studies often only highlight certain properties or features that users have found useful, not using methods able to systematically study and organize such data.

Participatory design is political in approach, as it tries to mitigate the consequences of unequal power relationships between stakeholders in a design process to ensure influence for the weaker party. There are, however, gaps in research, concerning power dynamics in PD settings (Light, 2010; Holland et al., 2010), but also specifically concerning the impact of designers' approaches on the users' possibilities for participation (Markussen, 1996; DiSalvo et al., 2007; Steen, 2011). Markussen (1996) pointed out the significance of different social conditions between users and designers and critically questioned what makes certain user suggestions better (in the eyes of the designers) and how designers judge users' contributions – questions still relevant today. Lindquist (2007) as well as Karasti (2010) highlighted the need for self-reflection in PD. Karasti argued that the PD researcher/ (designer) “remains the best kept secret” (2010, p. 89) and proceeded to say that PD researchers' “associated roles, activities, knowledge, agencies, relationships and responsibilities” (p. 89) are hardly articulated. Several authors (Bergvall-Kåreborn & Ståhlbrost, 2008; Light, 2010; Holland et al., 2011) have presented criticisms or pointed out these and similar aspects of PD as being in need of further exploration. This dissertation will contribute some answers or partial answers to these questions.

Summary of studies

General aims of the dissertation

The general aim of this dissertation was to explore users' contributions and user influence in a PD process. Young carers' views and ideas of a WBSS were explored, both from their perspective as prospective users and from their perspective as co-designers (Studies I and II). Furthermore intention and use of the development WBSS and its implementation were compared in order to investigate conditions for redesign (Study IV). The conditions for user influence were explored as a function of users' and designers' different social conditions and as a function of the designers' internal work and the conditions for their work (Studies II and III).

Context of the studies

Building a WBSS is a procedure that in its entirety is complex. One of the first missions in the design project was to find technical competence, given a certain time frame and certain financial restraints. Although an "in-house solution" probably would have been money-saving, other problems with such a solution could be anticipated. Official domains, like the Vårdal Institute and the University of Gothenburg, use to be very cautious about graphical and stylistic appearance, hence limiting the freedom to frame and design a website. Moreover, it was suspected that an in-house solution would render low prioritization for technical support. Private alternatives did not fit the financial frames. Finally Innovation Lab at the University of Borås was found and offered the needed service: research supporting systems development. At that moment the decision was made to put the website on a private web hosting service, as this would guarantee the freedom that was needed for the PD setting.

A parallel process was to find a skilled journalist for tasks such as writing articles and performing interviews for the website. The journalistic work should primarily be based on the discussions and suggestions emerging in the design meetings with the prospective users (Study II), but also on the needs and suggestions identified in the previously performed interviews (Study I).

At this stage of preparations, the future operative phase of the WBSS was considered. The responsibility for the anticipated ask-answer functionality and the forum board (e.g. moderation) was discussed and in connection to this, so were questions of security and handling of incidents. Another

important issue was to financially assure journalistic competence during the operative phase so that the WBSS would not stagnate. Finally, concerns about the post-study phase were mooted. If the WBSS turned out to be useful it would be ethically and financially desirable to engage a suitable organization to proceed to run it. While some of these questions were solved in a later phase, most were satisfactorily settled and the work could begin.

Several things needed to be coordinated. The prospective users who had agreed to participate needed to be contacted and engaged. A suitable place to meet had to be found and a first meeting between the work group (half of the young users) and the project representatives (the author of this dissertation, the journalist and one person from Innovation Lab) had to be arranged. Waiting to comment on the first version of the WBSS were the test group of users working from their homes. The aim was that they would try out and comment on every new version of the WBSS that was developed by the work group. Although four of the intended user participants (two from each group) dropped out the setting became sufficiently stable and functional.

Overall, the design meetings were fairly informal and unstructured. During the first meeting a laptop was available for use by the participants. It was used to look up websites of interest as reference during the discussion and exchange of ideas. At subsequent meetings the emerging WBSS was projected onto a screen during the design meetings. Each such version was based on the previous meeting's suggestions and ideas. This projected version worked as a virtual mock-up which could be interacted with and discussed. This virtual mock-up was also available to everyone reviewing it from their home. Suggestions and comments from the test group, where available, were brought up in the design meetings.

As the work to be done by the DT between the meetings with users (Study III) became overwhelming, the release date of the WBSS was postponed by 14 days. The amount of work that had to be put into content creation and the additional work to make the site look as requested was extensive, necessitating an increase in work time on several occasions. Innovation Lab needed to adapt the platform to current needs, such as implementing different functions and helping out with emergent problems, which took up a great deal of time. The work triggered conflicts due to role ambiguities, differences in views and commitment to the work, and dysfunctional technology. The distributed environment that the DT worked in was probably another contributor of conflict. This implied that most communication between the members was by e-mail, although it was possible sometimes to arrange physical meetings. In total, e-mails cleaned up from duplicate texts covered about 250 fully written A4 pages.

On 16 June 2009 the WBSS was opened to the users in a randomized study

(Skärsäter, Ali, Elf & Krevers, 2011) and it ended 8 months later, on 16 February 2010. The work to find an organization prepared take over responsibility for the WBSS proceeded. On several occasions negotiations about the continued management of the WBSS ended with a “no” or, in the best case, an offer to use selected material on their own website. Finally, Suicidprevention i Väst (SPIV) (Suicide Prevention in the West) were very interested as this kind of website was in line with what they had planned themselves. However, they wanted to use their own graphical design, which was produced in cooperation with young people. While the amount of material was reduced the foundational idea of the WBSS was kept. How real users used this new form of the WBSS, Livlinan.org, was investigated in Study IV.

Study I

Aim

The aim of Study I was to explore young carers’ support needs, related to (1) their care situation; and (2) a hypothetical WBSS.

Participants and setting

The participants were recruited in Sweden, by means of advertisements, leaflets and websites. Inclusion criteria were: (1) being aged between 16 and 25; and (2) being close to and supporting someone with mental illness. The exclusion criterion was not being able to understand, speak or read Swedish. Twelve (out of 14) young people were included in the study; one person lost interest and another did not meet the inclusion criteria. Participants were unevenly distributed with regard to gender (there were three male and nine female participants). The participants were from different backgrounds representing different types of care situations. Some had long-term experience of caring for someone with mental illness and some supported or had supported more than one person.

Data collection

Data were collected through a focus group meeting (n=4) and individual interviews (n=8). The individual interviews were conducted as either face-to-face interviews or telephone interviews. A semi-structured interview technique was used in all settings, following an interview guide. The interview guide consisted of questions about the carer and the one cared for,

the care situation in a time perspective, and questions about Internet use and opinions on a hypothetical WBSS. In all settings, interviews were tape-recorded and transcribed verbatim.

Data analysis

Before the coding process all the authors read the interviews and familiarized themselves with the data. Data were then analysed in a problem-driven content analysis inspired by Krippendorff (2004), where one interview was regarded as a unit of analysis. The coding process was performed in three domains: (1) expressed support needs related to the care situation; (2) expressed support needs related to the hypothetical WBSS; and (3) inferred support needs related to the care situation. Codes were revisited and transcripts were reread in a circular process, where different themes describing support needs were tried out. Finally, the codes were organized into three themes, and further processed into sub-themes. The process could be viewed as a process of finding the themes that offered the best descriptions of the data. Codes from domains (1) and (2) were primarily organized, while codes from domain (3) were added only if they represented a need not already present in the other two domains. The inference process consisted of judgements of support needs based on the interview data. The first author of Study I (M.E.) coded the material in ATLAS.ti (Science Plus, 2010). The first two units of analysis were reviewed by the second author (B.K.) and discussed, before continuing the analysis. The organization of codes into themes was continuously discussed, and reviewed also in a research seminar.

Results

Three types of support needs were revealed: knowledge, communication, and outside involvement. They are presented with their sub-themes.

Knowledge – understanding mental illness, managing the mentally ill person, and self-care. The need for knowledge concerned facts about the illness, its course and consequences, but also other carers' stories and experiences. Advice from different sources was expressed as important, while knowledge on principles of self-care was inferred as an important.

Communication – shared experiences, advice and feedback, and befriending. Participants expressed the need to communicate with peers and exchange experiences. They also called for possibilities to get advice from and sound out their thoughts with someone. The wish was expressed that communication could be extended to real-life meetings.

Outside involvement – acute relief, structured help, and health care

commitments. There was also a need for others' action on the participants' situation. Participants sometimes felt that they or their family were in a state of crisis and wanted someone to take over and bring relief. In a longer term they expressed needs for family (and other similar) support. Participants also expressed views on how health care worked in general, and called for more thought-out, persistent and caring health care.

Conclusions

Study I concluded that there are common support needs which a WBSS for young carers shares with WBSSs directed at other groups, and that these could be met by offering support for knowledge and communication needs. As needs for real-life and outside involvement cannot be met in a web environment, it was suggested that these be facilitated through a localized WBSS mediating relevant resources via a dedicated staff.

Study II

Aim

The aim of Study II was to explore how the social conditions of the participating young carers would inform the design process and how their perspectives differed from the perspective of the project representatives.

Participants and setting

Studies I and II had a joint recruiting process and equal inclusion/exclusion criteria. Twelve individuals (four male, eight female) were included in Study II and the design of the WBSS. Eleven had participated in the preceding interview study, while one wanted to take part in Study II only. They were asked whether they wanted to take part in a work group or in a test group. Participants living considerable distances from where the meetings took place (n=6) chose to take part in the test group only, while the remaining participants chose the work group. Four people, two from each group, did not reply to reminders and never showed up, leaving eight participants in the study.

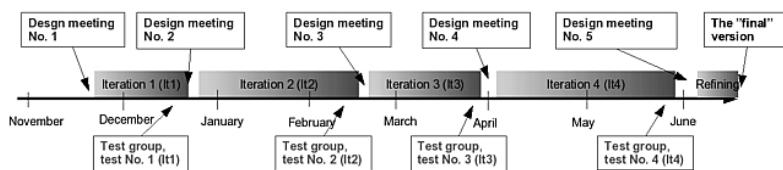


Figure 1. The design process and its elements – a timeline overview.

Elf et al., *Informatics for Health and Social Care*, 2012; 37(4): 203–216, copyright © 2012, Informa Healthcare. Reproduced with permission of Informa Healthcare.

The design process followed a chronological order where design meetings, practical design work based on these meetings, and the test group's contributions followed upon each other in an iterative process (Figure 1). The results of each iteration were made available to the test group for their work and presented in the work group for further discussion. The test group were given 2 weeks to give comments and perform test tasks.

Data collection

Data collection included video recordings of the five consecutive design meetings with the work group participants and three project representatives. Each meeting lasted approximately 1½ hours. Data also included written feedback on open-ended questions answered by the test group. These data were used as supplementary data and were collected via e-mail.

Data analysis

In the first step, the video material was analysed using content analysis, as inspired by Krippendorff (2004). The data were approached by looking at the material several times and taking notes. The process of identifying central topics was supported by including researchers (H.R. and J.L., second and third authors of Study II) who had not been involved in the PD process. A software application, AVxCAT (Remy Dodin, 2009), with the capability to code, comment, and categorize video clips was used. A video recording of one meeting was regarded as a unit of analysis. Each unit was coded, with codes held as close to the content as possible. One code corresponded to one delineated sequence of videos. Codes were revised until they were found to be relevant and similar in terms of level of abstraction. Codes, in close association with their content, were then organized into different themes, in a bottom-up/top-down process. This process continued until the themes

represented the whole data corpus in a relevant and consistent way. A number of themes were generated, which in turn were reduced to four separate themes. In a further process, each theme was divided into sub-themes.

In the second step, written comments from the test group participants were sorted into the same themes and sub-themes as above. Representative quotations were chosen and included in the Results section.

In the third step, the content of each sub-theme was scrutinized for different perspectives emerging in the series of meetings. Dewey's concept of *public* was applied and different perspectives were viewed as emanating from the different publics of young carers and project representatives.

Results

The design meetings followed four main themes related to the design of the WBSS. Each theme will be described below, while the sub-themes will only be named.

Communicating the message – targeting, displaying competence and a serious attitude. For users to understand their needs and to know that help is available was viewed as essential. It was suggested that knowledge about a WBSS should be conveyed by personnel at key places such as health care centres, youth health centres and youth clubs. To demonstrate competence a WBSS must have a considerable amount of content and a professional, plain and straightforward appearance. The participants found it crucial for the WBSS to have a serious attitude towards itself, its field and its visitors. The two publics differed in their views on how knowledge should be handled and in their views of publishing content for amusement.

Ideational working principles – support goals, methods and means of support. The idea of normalization was a goal that was often mentioned, as was the provision of information, knowledge and advice. It was important that the means to achieve these goals should be close to practice and should be usable in everyday life, like providing a system based on symptoms, making it possible to find a probable diagnosis as well as suggestions for support interventions. Providing facts and others' experiences of living close to persons with mental illness was viewed as essential. Use of video material was preferred to written material. Enabling peer support and connections to other young carers was likewise viewed as essential. The two publics differed with regard to whom they viewed as the recipient of support, the aim of the support and what roles users would be able to take.

User interaction – publicity versus privacy, risk management. This theme concerned issues coming into focus when people meet online. The option for

users to give advice in private was raised, as this was sometimes felt to be more adequate, and risks and risk management were discussed. The question of anonymity, and crossing the line between private and public was raised. It was said that sometimes total anonymity is needed when communicating through forum boards or blogs, anonymity not even associated with a nickname (i.e. a fictitious name often used on forum boards). Rules, moderation and banning were considered standard measures to be used and different perspectives on censorship, control, responsibility and human resources were discussed. The two publics differed in one aspect of publicity and privacy, namely, whether it should be possible to receive answers to questions privately or whether answers should always be publicly answered for the benefit of all users.

User interface – user adaptation, structural issues. Although adaptation of content was seen as problematic, due to a heterogeneous user group, an easily understandable language was considered important. A “find local help” box was considered a useful function. An intelligible structure of the WBSS was judged to be crucial for the website to be able to hold a considerable amount of information, which was deemed necessary. The two publics differed in one structural issue, namely, wanting a clear, condensed and concise front page versus choosing a more cluttered front page, the front page being viewed as a “mirror of the site”.

Conclusions

Four essential themes were revealed, and suggested as key parts in the design of a WBSS directed at young carers. In striving for shared understandings within PD, central differences in perspectives between users and designers may be shadowed and overlooked. Early user involvement and theoretically informed analyses of the PD process itself are suggested to be crucial for revealing such differences.

Study III

Aim

The aim of Study III was to explore, from a process perspective, how the designers’ internal work affected the potential users’ opportunities to influence the design process.

Participants and setting

The four participants included in Study III were all members of the DT. They were: (a) a journalist and information officer with skills in typography; (b) a psychologist and PhD student with a master's degree in information and communications technology (ICT) and learning; (c) a systems developer and industrial PhD student and (d) a newly graduated systems architect. The first to be recruited was the first author of Study III (M.E.). The other participants were contacted by M.E. by phone and invited to participate. The members of the DT were geographically distributed, and most of the communication between the members was via e-mail. In practical terms, the DT was split in two parts, with (a) and (b) mainly working on content creation and (c) and (d) mainly working with technology solutions.

Data collection

Three types of data were included: e-mail conversations between the members of the DT, ordered by date and time, verbatim transcriptions from a focus group meeting, and quantitative data based on the e-mail conversations including the number of quotations in each category obtained by the qualitative analysis of the interviews. An interview guide was used in the focus group interview. The interview started with questions about the participants' work background, and then focused in on each design iteration and the ways in which the designers addressed any issues that arose during the design process.

Data analysis

The text-based data were analysed in a grounded theory process (Corbin & Strauss, 2008). First, the transcribed focus group interview was coded line by line by M.E. Codes were reviewed in a constant comparison with respect to similarities and differences in meaning, and then brought together into categories. Memos were made throughout the analytical process. Precautions were taken to establish trustworthiness of the analysis, since the first author (M.E.) was also a member of the DT. The second author (H.R.), who was not involved in the research project during the design process, performed a parallel analysis. The two analyses were compared several times during the analytical process, until the analyses were found to be concordant and representative of the whole data corpus.

Next, the e-mail correspondence was analysed and then merged with the analysis of the interview data, which resulted in the addition of a number of sub-categories to the latter. Further analytical work resulted in an overall

reduction, ending in six sub-categories which were organized into three main categories. In each sub-category, the coded raw data were examined and split into design periods, each of which covered a period of the internal work of the DT, following each meeting with the users. Representative codes from the e-mail conversation within the DT were collected from each design period, and set up in a matrix to examine how different processes within the DT proceeded over time. The total analysis was iteratively discussed among the authors to enhance the trustworthiness.

In the quantitative data the percentage distribution of quotations between categories in every design period was calculated.

Finally, a theoretical model was developed, based on the e-mail data matrix and the quantitative data. Two major types of changes were observed over time in the matrix. These were conceptualized in accordance with the trends they were assumed to reflect and were represented in the model. Any changes over time in the percentage distribution of quotations in each category were noted and included in the model.

Results

Qualitative analysis

Re(creating) infrastructure – collaborating and communicating, finding a role. Collaboration and communication worked like “cohesive glue” in the design process, by keeping the DT members informed, solving operational problems and finding ways to do the work effectively. However, halfway through the process, collaboration and communication were increasingly used as tools to govern production, in order to reconcile new technical functionality or optimize work efforts. This change made increased demands on the technology used in the work. Along with the different types of commitment between (a) and (b) on the one side, and (c) and (d) on the other, the changing environment paved the way for an emerging crisis between the two parties. Members (a) and (b) made persistent yet unsuccessful efforts to find appropriate roles and a sufficiently delimited assignment in the team, due to mismatched expectations. This problem levelled off in the latter part of the process but all the same slowed down the progress of the project. However, along with the shifting needs in different phases the demands in the design process increased. There were changes in the individual members’ roles as well as in their workload so as to be able to adapt to these requirements.

Involving users – relating to users, judging users’ contributions. There was an initial exploring attitude towards the users, despite upcoming dilemmas

regarding participation. The DT had to consider to what extent they would develop solutions based on the users' suggestions before each meeting. Too far-reaching solutions might constrain the users' space for developing their own ideas, while the opposite might mean that the users would have nothing to respond to and that nothing would encourage discussion. Similar considerations were true for the balance between designers' and users' expression of views. About halfway through the process there was a notable change in attitude. The exploring attitude was replaced by a focus on the concrete production process, with increased experience of stress and need for efficiency. In the first half of the process the users' contributions were respected and valued. However, in the second half the attitude of the DT changed. Users' contributions were now more often judged amateurish, incompetent and insufficient.

Realizing suggestions – processing suggestions, relating to external frames. To realize suggestions implied continuous processing of suggestions. Initially this processing assimilated the users' contributions but as time went by, the DT perceived the process as too opaque and hard to anticipate. In the latter half of the design process, the focus was on the need for concretization of ideas and completion of the WBBS. While the atmosphere was positive and open to critical comments, the suggestions and ideas increasingly seemed to originate from the DT itself, with occasional suggestions to consult professional external designers. In the realization process the DT explored and tested the limits of the project frames. Time, finances, ethical dilemmas, interaction on web forums, and more, were discussed against relevant criteria, such as laws and guidelines, with and without the project management. From halfway through the process, financial and time constraints became central. Issues of scarce resources of both personnel and time were raised several times in connection with the ability to meet the requirements of the project. Individual members prioritized their time to a higher degree and any technological obstacles to doing the work were experienced as a waste of time.

Quantitative analysis

Table 1 shows the percentage distribution of quotations per category in each design period, including an additional period zero that began 1 month before the first meeting. As can be seen, there was a steady decrease in the category *Involving users*, with a concomitant increase in the sum of percentages in the other categories.

Table 1. Distribution of quotations per category, given as percentages of quotations in all categories for each design period.

Design period	(Re)creating infrastructure	Involving users	Realizing suggestions
0	19	48	33
1	32	30	38
2	39	16	45
3	58	15	27
4	49	6	45
5	49	1	50

Theoretical model

The categories revealed in this study could be viewed as different *areas* of activity that the DT were involved in during the design process. In the qualitative data a change was observed *across* areas (Figure 2) and over time in what we label a *process dimension*. There was an overall shift from an exploratory approach (the zone under the curve) to a productivity approach (the zone above the curve). We suggest that such a shift in approach can be explained by the external project timeframes, but in this case it was also triggered by a misalignment between the DT and the users; the DT members felt that they were not able to deliver enough content in time, a view that the users shared. In addition, a shift in a *knowledge dimension* was observed – that is, in the view of whether it would be users’ knowledge or expert knowledge that would be deemed desirable. This shift – including the areas *involving users* and *realizing suggestions* – is hypothesized to be entailed by the shift in the process dimension.

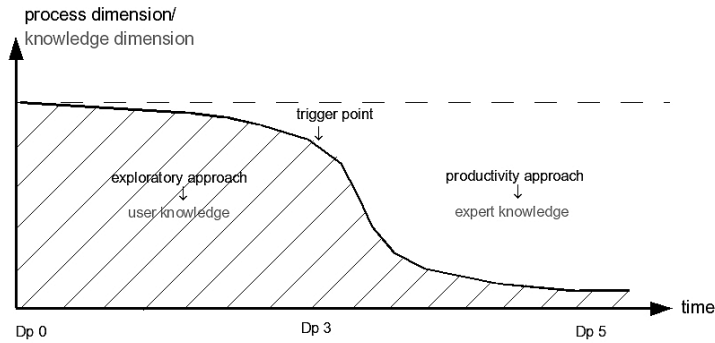


Figure 2. Change across categories over time, a shift to a productivity approach.
Dp = design period.

The quantitative results revealed a change *between areas* over time (Figure 3). The area *Involving users* decreased in relation to the other two. We interpret this change as a sign of how the members of the DT prioritized the maintenance of the infrastructure of their work and the realization of existing suggestions instead of involving users. While it is still true that many of the users' contributions were integrated in the realization process, this result suggests that the focus of the DT had moved in another direction.

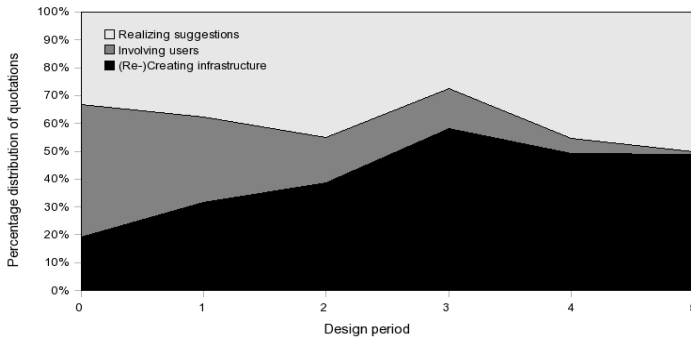


Figure 3. Percentage distribution of quotations between areas.

Conclusions

It was concluded that users' opportunities to influence the design process were informed by how well the DT were able to handle the shift from an exploratory approach to a productive approach. If some critical conditions

relating to the DT are addressed (attitude to PD, preparative team building, the team environment, and how users are involved) it may be possible to obtain a better balance between the exploratory and productive approaches of the DT in the latter part of the process. This, in turn, can promote increased user influence.

Study IV

Aim

The aim of Study IV was to compare the intentions and use of two WBSSs. One was used in an experimental setting, while the other was an implemented version used in a natural setting.

Setting

The two WBSSs Molnhopp.nu (MH) and Livlinan.org (LL) were available on the Internet; MH as a saved, but not generally available copy and LL as an operative website. Molnhopp.nu was the original development website tried out in an experimental setting and LL was a redesigned and implemented version of MH. Both were fully functional and connected to Google Analytics.

Data collection

Two sets of data were collected. For set one, both websites were systematically browsed, while page name, web address and page level in the page hierarchy were noted. For set two, web page statistics were acquired from Google Analytics. These data were exported to Excel sheets and cleaned up according to a specific procedure. Remaining data included page views, unique page views and average time spent on page and were used for analysis.

Data analysis

The pages on each website were categorized in two ways: type of page, and page content. Two types of pages were identified, intermediate pages and end pages. An “intermediate page” was defined as a page that gives entrance to a number of pages concerning similar topics, in turn constituting the end pages. As intermediate pages by nature have more page visits, only end pages were used in the analysis. Altogether, MH had 128 end pages and LL 104. Taking

as a starting point the young carers’ concepts as talked about in the former design meetings, 16 types of content were identified and named on the websites. The collected data were in turn connected to each category of page and in this way two types of profiles of the websites could be made. To obtain a profile of intention the pages in each category on the respective website were counted and the percentage of all the pages in all categories was calculated. To obtain a profile of use the percentage of all unique page views in each category was calculated and related to the total of unique page views in all categories. To get a clearer picture of use, the average time per page in each group was calculated as well as the quotient between page views and unique page views. The latter value says something about the frequency with which users on average go back to the same page during the same session and is here labelled *in-session revisiting liability*.

Results

Results are presented as graphics. The abbreviations for categories in Figures 4–11 are given in full in Table 2.

Table 2. Categories and their abbreviations

Practical advice from young carers and experts	A	Interviews with support organisations	Iso
Book reviews	Br	Interviews with young carers	Iyc
Facts about specific diagnoses	Df	Lists of links	L
Forms for different kinds of contact	Ffc	News related to mental health	N
General facts about mental health	Gf	Polls	P
Information about the website	Iaw	Published questions and answers	Q&a
Interviews with diagnosed persons	Idp	“Soft facts” about recognisable situations	Sf
Interviews with experts	Ie	Short interviews with support organisations	Siso

Profiles of intention

Molnhopp.nu’s profile of intention was different from LL’s (Figure 4). One observation was that MH had a broader content than LL. This was reflected by the fact that there were more categories, 15 for MH versus 12 for LL, and a more equal distribution among the categories. Livlinan.org, by contrast, was dominated by fewer categories occupying a greater part of the content. Regarding the two largest categories, the two websites were similar. They focused on descriptive and narrative expert knowledge about psychiatric diagnoses (Df, Ie), although for LL, these parts were slightly more dominating, due to a larger focus on the descriptive part (Df). It may be said that both websites were dominated by the provision of expert knowledge. However, LL balanced this domination to a higher degree by providing more content directly related to the situation of the young carers (Iso and Iyc). In MH, similar content had to be shared with a continued focus on the disease and health-related facts (Idp and Gf).

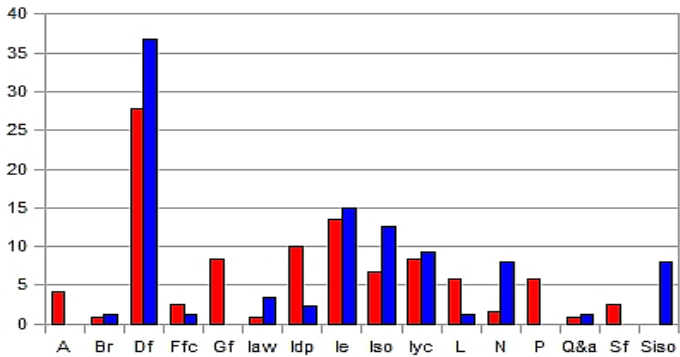


Figure 4. Categories related to intention on MH (grey) and LL (black).

Profiles of use

Regarding their profile of use, MH and LL (Figure 5) showed a similar distribution of categories as in their profiles of intention, i.e. a broader content for MH and a more narrow content for LL, where fewer, larger categories occupied a greater part. Regarding actual use, both websites’ users focused on diagnostic facts (Df). Link pages (L) were also relatively highly ranked on both sites, but there the similarities ceased. In MH, users had a fairly even focus on many categories, showing a more tentative search or orientation behaviour. By contrast, LL’s profile of use demonstrates a clearer

focus of interest. The largest categories, apart from those already mentioned, are about the situation of young carers: users liked to read others' questions and the answers (Q&a), and to read about the situation of other young carers (Iyc). An observation was that both user groups showed a very low interest in reading about the experiences of persons who themselves had or had had a psychiatric diagnosis (Idp).

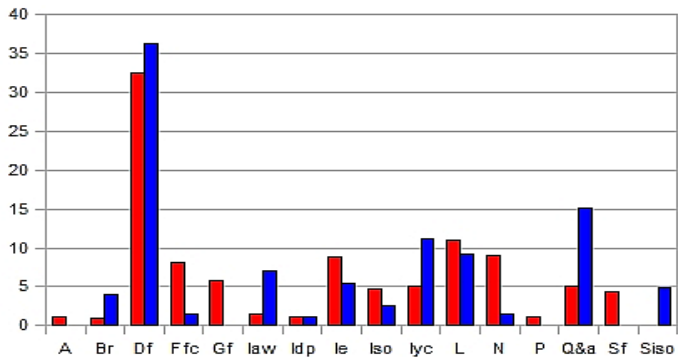


Figure 5. Categories related to use on MH (grey) and LL (black)

To obtain a other perspectives on use, supplemental measures were included. These were *Average time on page per category* and *In-session revisiting liability per category*.

Average time on page. On each website it can be seen that some often visited pages are also visited for a longer time; on MH, this specifically concerned the links (L) and news pages (N). On LL the corresponding content was that relating to young carers' experiences (Iyc, Q&a). However, the most conspicuous differences between MH and LL (Figure 6) are that LL's users overall spent more time per page. A further observation is that some categories not visited often still have high time values, implying that they are fairly interesting for *some* users. An example on MH is the category conveying experiences of young carers (Iyc) and on LL reviews of relevant books (Br). On the other hand, some categories were rated low on both page visits and time spent. It can be assumed that low rates in both time spent and number of unique page visits are an indication of a less interesting category or a category that needs to be further developed to be of interest.

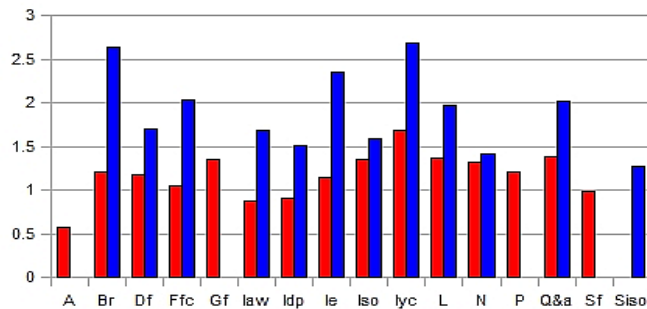


Figure 6. Average time/page, in minutes, on MH (grey) and LL (black).

In-session revisiting liability. This value was fairly evenly spread out across the categories in both MH and LL (Figure 7). However, overall the in-session revisiting liability was higher on MH, showing that the users of MH generally tended to browse from and then back to the same page during the same session to a greater extent compared with the users of LL.

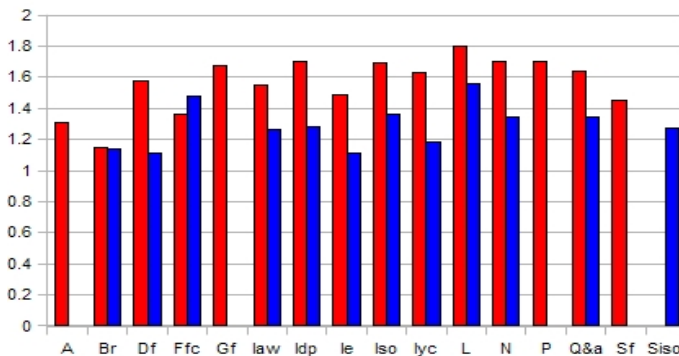


Figure 7. In-session revisiting liability across the categories of MH (grey) and LL (black).

Conclusions

Although a PD process may enable a good enough adaptation to future use and highlight the most important types of content in web health portal projects, it will not be able to fully anticipate it. Continuous use of web page statistics and recurring involvement of users are suggested. However, it is

also concluded that the context of use is critical and that data collected in an experimental setting may be misleading and not reflect real use. Consequently, usage of natural settings for user feedback is recommended.

General discussion

As stated in the Introduction, this dissertation follows two lines of investigation. The first is about specifications. These include the support needs of the young carers in this study and how the WBSS can meet these needs. It also indirectly investigates the real users' views by comparing the intentions of the WBSS (informing the design before use) with the real users' actual use. The other line of investigation concerns participation. This includes designers' and users' different views as members of different publics and the conditions for users' influence in the design process, set by the design process itself as well as by the designers.

Users' perspectives and implications for design

Study I concluded that most needs for knowledge and communication could be met in a Web 2.0 context but that issues such as modes of presentation, anonymity, and barriers for use have to be considered to increase the willingness of users to access a WBSS. Other studies have similarly indicated that the most frequently used aspects of web support for youths relate to sharing experiences, seeking information and providing/seeking support and advice (Giesbers et al., 2010; Nordfeldt et al., 2010; Stinson et al., 2008). Video recordings were a requested presentation mode in the present studies, as also reported in other studies as a means to attract youth (Stinson et al., 2008). Media technologies and games have been proposed as a way to reach specific target groups (Giesbers et al., 2010; Stinson et al., 2008), e.g. boys, while scenario-based games have been shown to be effective in teaching life skills (Pacifci, White, Cummings & Nelson, 2005). Furthermore, anonymity seems to affect user interaction in unexpected ways, depending on the individual's interaction style (Wodzicki, Schwämmlein, Cress & Kimmerle, 2011). Tanis and Postmes (2007) report that people participating in online discussion in their study felt more secure and more satisfied with both the medium and the own performance if visual cues to identity were absent. They concluded that the absence stimulated a more group-oriented behaviour. Barriers to use also have to be considered, such as password requests (Nordfeldt et al., 2010) and psychological reluctance to be associated with a disease (James, 2007; Nordfeldt et al., 2010), as also indicated in Study II. This basic type of online support, meeting needs for knowledge and communication, will henceforth be referred to as *core support*.

Study I reveals that the young carers' view was that "the web" might be useful as a starting point or a base for getting support. However, they did not view that as sufficient. The young carers also wanted to be able to deepen their peer contacts via e-mail or a personal message system and perhaps extend these online contacts to real-life contacts. This further elaborates what was concluded about previous research in the Introduction: (1) Internet-based support in general suits a limited group, often including young people with mental health problems; (2) there are indications that their choice to use online support is a secondary rather than primary choice; (3) face-to-face support from others, such as friends or parents, is regularly preferred to online support; and (4) the reason for choosing online support in the first place is the anonymity offered in online support, and its benefits, giving a feeling of privacy and a decrease in the feeling of being judged. Giesbers et al. (2010) investigated the use of a WBSS for young people (>12 years of age) who had a parent with cancer and found that extending contacts made on the WBSS to "real life" was the most common support-seeking behaviour after sharing experiences and encouraging/supporting each other. Lack of understanding from the surrounding environment is common among young carers in general (see, e.g., Thomas et al., 2003), as also reported by Giesbers et al. (2010). Together this information strengthens the conclusion from Study I, where it is suggested to add the aspect of *localization* to the core support, thus anchoring the WBSS in geographical areas.

Localization of a WBSS would facilitate real-life contacts and the representation of external services such as health and social care services, relevant authorities and support groups. Risks associated with real-life contacts have to be seriously evaluated and taken care of, however. It is known, for instance, that youth suffering from depression and loneliness are more prone to take up contact with strangers (Ybarra, Alexander & Mitchell, 2005) compared with youths who feel well. At the same time, those with poorer mental health are more prone to use online support. Another challenge in offering localized support is to include areas that are big enough to be inhabited by a sufficient number of youths to preserve anonymity, but at the same time small enough to have some kind of geographical proximity. Study I also stresses young carers' need for outside involvement, needs of acute relief from the caring situation and need for structured help such as a family intervention. The young carers also wanted to be included and listened to by health care and wanted health care to be more responsible, persistent and well thought through, and to consider both the patient and the close other. A localized support has the opportunity represent external services close to young carers. However, these needs also require the addition of a second aspect, *mediation*.

"Mediation" should be understood in the Vygotskian way (1978) to be a

process where the user can make use of resources on the WBSS as a mediating tool for thinking or acting (Rystedt & Säljö, 2008). Study I showed that young carers wanted to know about external services, and how to reach them and they suggested that a WBSS should provide links to these resources. At the same time, the study revealed their lack of trust, which has also been reported in other studies (Becker, 1995; Grant, Repper and Nolan, 2008; Thomas et al., 2003). Furthermore, James (2007) reports that young people in general experience barriers to accessing such services. James mentions their restricted experiences of health care and how health care is structured; he also mentions feelings of shame and reports that young people do not necessarily connect their problems to their health status. Marcus, Estra, Eastwood and Barnes (2012) similarly conclude that young people may view the mental health care system negatively and feel disconnected from it. They suggest development of resources and services that allow young people to feel connected and empowered.

Hence, to make external services accessible, for example by providing links, is good but not enough. Becker (1995) and Cooklin (2006) both suggest that young carers may need someone who they feel can represent them and act in their interests. Linked to this suggestion, Study I suggests that a WBSS ought to function in a similar manner, by letting a dedicated web staff develop contacts with and explore external services and then provide this knowledge on the WBSS. Such rich material is necessary to make these services more visible, transparent, and familiar to the young carers, i.e. to provide availability to their local cultures. Increased familiarity can prepare and encourage young carers to take the step and make contact when this is needed. In this way a WBSS can serve as an effective mediating tool. Several studies indicate that human involvement in computer-mediated communication is essential, for example to ensure continuity in web-based CBT interventions (Andersson et al., 2009), to ensure elderly use of technology support (Conci & Chiara, 2010) and to increase participation in online educational programs (Jordan & Osbourne, 2007; Brouwer et al., 2011). Study II indicates that such involvement must be made visible and permeate the WBSS. This is the reason for introducing a third aspect or principle, here called *personification*.

Personification aims at the WBSS's expressed or perceived identity. Statements by the young carers in this study describe a web support that behaves and is perceived as a person or a team of persons. Knowledge presented on the WBSS should not merely be linked to, but should be produced by "the WBSS itself" and physically kept within it. To display competence and have a serious attitude seemed to be the overall prerequisites for credibility and an essential part of the WBSS's identity. Furthermore, both competence and a serious attitude seemed strongly connected to commitment

and devotedness. This view of the WBSS identity suggested not only a surface identity but also an in-depth approach that the WBSS and its “managers” should adopt. The young carers’ emphasis on the need for transparency, for example pertaining to knowledge about who answers questions, who writes the texts, pointed in the same direction. In summary, the website should behave as an entity, showing caution, competence and a serious attitude, mirroring a knowledgeable, respectful and empathic human being. It should be possible to relate to and trust and not just be another source of information and exchange.

From treatment to tool

When online support is evaluated in research, it is often evaluated as a *treatment* per se and with specific outcome measures like symptom reduction (Barak et al., 2008). Such evaluations may be fair with regard to treatment of panic disorder with Internet-based CBT or an educational online program for handling diabetes, for example. However, considering young carers and the needs and views expressed by them, and adding to this the number of studies showing young people’s general preferences for personal support one might question whether a WBSS directed at young carers should be used and thought of as “a treatment”.

For a person with diabetes, a core support may be perfectly adequate. It is likely that this support is part of a programme, maybe as a kind of aftercare or complementary care. If this individual has no other problems he or she is not primarily an “exposed” person. He/she needs no other external support: the core support is sufficient. Some external support may be useful but will not dramatically change the diabetes.

For a young carer, the core support may be just partly adequate, and in need of complementary support such as: real-life contact with others (localization), an active web staff providing help with familiarization with local external services (localization, mediation), and a caring and competent support (personification). Such support cannot provide either real-life contacts or external services, but promote the connection to them.

What is proposed then is offering a web-based tool that is made to support the creation of a context that young carers can use. The core support offers opportunities to learn by facts and other’s stories. Moreover, it offers possibilities to connect to peers. The additional parts facilitate real-life contacts by localization and availability to the cultures of external services. The tool offers a skeleton but not a scary one, a scaffolding environment, a facilitator in reaching the support these carers may lack. In Le Dantec et al. (2010) a communication central was developed together with homeless

shelter residents and case workers. The residents' interest in developing a social infrastructure was highlighted. Palzkill-Woelfer's and Hendry's (2009) study describes a similar approach, although not focused on web-based artefacts, where the aim was to structure information to homeless youths in a way that better supports an organization of their life. The function of Vstreet.com (Pacifiki et al., 2005) can be understood in a similar way, inasmuch as it tries to extend support from agencies to at-risk teens in transition to independent living. Vstreet.com has several components, one of which is the use of scenario-based games to train social skills such as job seeking. Such games seem to be useful, but probably require a stronger framing than seen in a WBSS. Usability research (Nielsen, 2001) has repeatedly shown that web users tend to search for content with immediate usefulness. Study II similarly reveals such an expressed preference among the user participants. Therefore, a skills training game may be too general and far from the real need.

In these cases of design, the main goal seems to be to create context, structure and opportunities, rather than achieve health benefits. All these cases seem to require more active involvement in the background. These forms of support are not built as treatments based on consequent actions to reach specific goals, but rather, are based on supportive structures to promote users' own actions to connect to a needed structure in their life. Technological artefacts are used as tools to mediate this action. These tools are provided with "ammunition" by the humans working in the background as an inevitable part. Drawing on what has been said before, such a model may be effective in capturing young people in the periphery, who feel in need, who are reluctant to seek the common health and social care and who are not in a state or have the opportunity to seek support among friends and parents.

The sketched model has some parallels to Kanstrup, Glaseman and Nielsby's (2010) design directions for design of information technology (IT) services to support chronic diseases. Theirs is a design framework developed in design work together with families living with diabetes. The authors use the concepts *learning design*, *community design* and *inclusive design*. "Learning design" corresponds to educational or knowledge-based programs. "Community design" adds the connection to the community, that is, to others with the same disease, for exchanging experiences, tips, etc. Finally, "inclusive design" aims to use technology to include the affected persons in society, for instance by using terminals in the grocery store, helping with finding the specialized food you need. This design direction is related to the concepts of *localization*, *mediation* and *personification* inasmuch as it offers means to involve the users in a societal context. The model outlined in this dissertation is based on Studies I and II on young carers close to persons with mental illness. Their support needs differ in character from the needs of most

youth with chronic diseases, by going beyond the “core support needs”, and they lack a structure taking care of these. Hence, the focus and content of support is different although the support may share similar structural aspects.

A final remark in this section concerns Study IV, which shows that specifications, even those made by involving users in a PD process, do not necessarily hold true when the designed object, a WBSS in this case, is exposed to the real users. This is not a flaw of the design process, but rather, a result of the impossibility to anticipate future use. Study IV also highlights a specific problem related to research projects such as the present, when research web health portals are evaluated in experimental settings. It suggests that this may be problematic as users may not behave as in a real-life setting, thus giving confusing feedback. Fleicher et al. (2012) stress another problem connected to research projects, namely low use, which may imply that data collected from users may be non-representative. A review (Bélangera, Bartletta, Dawesb, Rodrígueza & Hasson-Gidonic's, 2012) highlight a related problem that may emerge when health information technology is taken from one context and moved into another; i.e. it does not work as expected. The authors suggest involvement of users in the new setting when redesigning the technology.

Conditions for user influence

In the preface to this dissertation, an analogy was drawn between the study and an experience of different views in psychotherapy, demonstrated in a guided affective imagery (GAI) session. The experience led to the conclusion that assumptions of shared views, based on a seemingly cooperative climate, have to be scrutinized and viewed with a critical eye. In psychotherapy the psychotherapist continuously elaborates hypotheses about the client, which are based on what the client tells, but also on observations and self-observations of interaction between the two, in a process of transference and counter-transference. The client in turn is supposed to learn and make use of the psychotherapist's methods and become a working partner in the common project. The work to obtain a common understanding or shared views is continuous.

However, while self-reflection is an essential part of the psychotherapist's work, studies of PD seldom reflect on or articulate the designers' actions and agendas in the design process (Karasti, 2010). While Study II focuses on and articulates designers' and users' different views of the design object, Study III focuses on designers' internal work and how this is related to users' influence.

The design process in Study II was thought of as an issue assembling two publics acting on that issue, by involving themselves in a project to design a WBSS. The issue was the situation of young carers, while the social conditions of the two parties, designers and young carers, differed considerably. While designers and young carers in Study II agreed on many matters, they seemed to disagree on the most important and basic issue, namely the question of how the WBSS was supposed to help. The designers' views were characterized by a *learn-development* idea, while the young carers' views were characterized by a *need-now* idea, views clearly based on two different social conditions. It was apparent from the design meetings that some of these differences were not fully understood by the designers during the design process (e.g. the question of who is in need of help) and, moreover, that these differences were also the most critical. They reflect core differences between the publics while at the same time they represent blind spots for the designers. A conclusion is that shared understandings or shared views do not necessarily take place within a short time frame. Understanding and appreciation is a process, as also stressed in a study by Halloran et al. (2006) which explored curators as co-designers engaged in a technology project to create a new kind of visitors' tour. The authors point to the need for a process over time to enable the curators to learn to appreciate the possibilities of the technology. Halloran et al. conclude that "understanding emerges over time, distributed over several situated activities" (p. 117). Study II showed that not only do the co-designers need that time, but so also do the designers to be able to appreciate the users' view.

Time, and specifically time constraints in the design process, was one of the topics of Study III. This study explores designers' internal activities, i.e. their activities between the design meetings, to reveal how this work affects the conditions for user influence. In line with Gersick's (1988) finding in her grounded theory study, Study III found that there was a shift halfway through the design process, where the process seemed to enter a phase characterized by a strive to complete the project or product, i.e. to perform the tasks needed to deliver a WBSS on time. Moreover, along with this shift to a productivity approach, designers' preferred type of knowledge seemed to shift from knowledge based on user experience to their own and others' expert knowledge. Users' knowledge became questioned in different ways. The study proposes that the shift to productivity is the *reason* for the shift in the knowledge dimension, as expert knowledge is assumed to better fit the productivity requirements. These "micro"-level findings in Study III's productivity phase could be compared with the attitudes that others like Gould and Lewis (1985), Grudin (1993), Vredenburg et al. (2002) and Cajander (2010) found at an organizational level. All describe strivings for efficiency as an important reason for being reluctant to involve users.

Productivity requires rationality and rationality has little space for non-experts. In a study by Darses and Wolff (2006), designers are reported to view users as a sub-system to the machine that was under design. In their study the designers never met the users; instead, information was mediated through a project steering group who had met the users. A reflection on that study is that it shows what can happen when the designer does not have any personal contact with the user, demonstrating the ease with which we tend to instrumentalize a relationship. It is easy to imagine that productivity demands on designers have a similar effect, entailing a need to instrumentalize the users. Referring back to the analogy of GAI, the psychotherapist may make other judgements and use other kinds of knowledge when treating a client in order to meet requirements of a greater client flow, with apparent risks for the individual client. Therefore, what we see in Study III may be such an instrumentalization process where demands on productivity entail an instrumentalization of the user, resulting in less acknowledgement of the user's subjectivity, in turn leading to a more rational process which will tend to rely on expert knowledge. A well-known phenomenon in SIT is that members of the own group (the "in-group") feel more worthy than members of a group they compare themselves to (the "out-group"). Moreover, the in-group tend to experience themselves as individually differentiated compared to the out-group, who are experienced as "mass" (Tajfel, 1982). This phenomenon may be the basis for instrumentalization by preparing for the withdrawal of subjectivity.

Implications for the design process

Thus, Studies II and III together show that designers need not only to look at the user, his or her environment and the artefact, but to also include themselves and the design setting in critical reflection. The different publics from which designers and users come may entail crucially different views about what the design object is supposed to do. Likewise, time is a factor to reckon with when it comes to designers' understanding of the users' needs, and vice versa. Also, it may be a factor affecting designers' attitudes to users' experiences. Together, these are barriers in designers' understanding of users.

There should be several ways to handle these barriers. The designer must be aware of why he or she is engaged in a certain issue, i.e. have an awareness of the social conditions, and understand what impact these may have on the understanding of that issue. Less time pressure in the design process and a professional approach to user involvement should provide a better balance between exploratory and productive approaches and offer time for designers and users to understand each other. Higher frequency of meetings with users

in the latter part of the design process may decrease the instrumentalization process and promote higher user influence.

Reflections on methods

Qualitative research must be trustworthy, i.e. it must be possible to believe the reported findings. There are different approaches to trustworthiness. I have chosen to present a model proposed by Graneheim and Lundman (2004) based on a literature review that suggests that trustworthiness has three aspects. Although these aspects are described as separate they should be viewed as interrelated. *Credibility* is the first aspect. It concerns how well data and analysis are adapted to the focus of research. Diversity of data is important to obtain a richer variation of the phenomena under study. In the coding process, meaning units must not be too broad or too narrow or else there is a risk for either too little variation of meaning or fragmented meaning. Credibility also includes how well categories or themes cover data and how to judge similarities within and differences between them. The next aspect of trustworthiness is *dependability*. This is about the degree to which both data and the researcher's approach to data may change over time, e.g. as a result of what the researcher learns over time, by consecutive interviews. (However, in grounded theory, this is not a problem – a learning researcher is a better interviewer and can obtain greater depth in the data [*my note*].) *Transferability* is the last aspect described by Graneheim and Lundman (2004) and refers to the degree to which the research findings can be applied to other settings. Clear and distinct descriptions of the research context and process, together with rich presentations of findings, will enhance transferability. In the present research, trustworthiness has been addressed in several ways.

Participants

Recruitment of participants for Study I was done through leaflets, newspapers and websites, with poor response. Fewer participants than expected declared their interest in the study and the plan to use two to three focus groups could not be carried out. Consequently, both their representativeness and the recruitment method may be questioned. For example, recruitment could have happened through the social services or organizations working with this group. However, the chosen recruitment method can be defended. Firstly, the fact that these participants responded indicates that they were aware of their situation and feelings and position regarding mental illness. Hence, they were also able to talk about their situation in an informed way. Secondly, they showed a diversified background representing different care situations,

relationships and care burdens. Thirdly, the fact that they were not recruited through a social services programme or similar, may mean better representativeness of an important target group of the project, i.e. young carers not reached by community-based efforts.

Participants in Studies I–III have been sufficiently described for readers to understand the results in relation to their background. Furthermore, the descriptions have been in parity to the respective study's needs and to ethical considerations.

Data collection

We used several methods of data collection. *Focus groups* were used in Studies I and III. To not risk losing the persons who decided to participate, they were offered the choice between focus group and individual interviews (face-to-face or telephone interviews for those participants who lived far away). The aim of focus group interviews is to explore an area of specific interest for the researcher through the participants' creative dialogue (Tursunovic, 2002). A moderator should ensure that relevant questions are asked when needed to enhance discussion and further, that all participants have a possibility to express themselves. Of special interest in Study I and in the original plan to use focus groups was the method's assumed ability to reveal needs, motivations and values (Kuniavsky, 2003). Furthermore, focus groups are suitable for discussion of sensitive topics, and have been used in many such contexts (Wilkinson, 2007) although their suitability for this purpose will be dependent on the group's development and the moderator's manner and ability. In Study III there were some special reasons for complementing the mail conversation data with focus group data and not individual interviews. These were: (1) to use the group to remember together what topics, problems, solutions, etc. emerged; (2) to ensure that the members' different perspectives would have a possibility to be represented in every topic; (3) to make the data collection process transparent to the participants and to readers of the study as one member was also a researcher; and (4) to obtain data that could give a context to and another perspective of the process. Reflecting on our own use of focus groups, they provided more dynamic range than did individual interviews. It was easy for participants to refer and connect to what other participants said. It also became apparent that the focus groups enabled some participants to express things they had never expressed before, using the group context. A general impression was that the participants themselves gained quite a lot from the opportunity to discuss and exchange views and experiences with each other about a topic that was close to their hearts.

Individual interviews were performed either face to face or via the telephone. In an interview (focus group or individual) it is important to remain non-directional throughout the interview and try to keep questions open-ended. An interview setting is a sensitive setting anyway (Kuniavsky, 2003). People may fear conflict, embarrassment or being seen as stupid. They may feel they are not listened to, that there is time pressure or that they may feel forced to give an answer. Regardless of whether such fears are imagined or real they may affect the participant's answers and the interviewer must be observant of him/herself as well as of the person he or she interviews. These cautions do not necessarily make the interview impersonal. Both interviewer and the interviewed must be allowed to feel comfortable (Kuniavsky, 2003). The individual interviews that was performed tended to go deeper into personal experiences, feelings and thoughts, while at the same offering a greater challenge in obtaining rich answers on the topic of interest. In a focus group, several perspectives will automatically emerge, while in the individual interview setting, the exploration of different perspectives has to be handled to a higher degree by the interviewer. From our data, it appears that the telephone interviews in our study were somewhat more personal and more open-hearted compared with the face-to-face interviews. We do not know the reason for this, but one possibility is that the combination of personal contact and relative anonymity made it easier for the interviewed person to talk. One review of telephone interviews versus face-to-face interviews (Novick, 2008) concludes that there is no evidence that telephone interviews produce lower data quality. Rather, telephone interviews may allow respondents to feel relaxed and more able to disclose sensitive information. Another clue to this finding may be found in Colombotos' (1969) study exploring differences between telephone and face-to-face surveys. The author in that study reported that persons interviewed face to face tended to give more socially acceptable answers than those interviewed by telephone.

Sensitive settings in data collection

While Study I is an exploration of the needs of young carers with regard to their life situation and a hypothetical WBSS, it is also a prerequisite for performing Study II. Participatory design, which typically takes place at a workplace, often makes use of ethnographic methods, thus allowing the study of work where it happens, day by day. This gives the advantage of a close-to-practice knowledge with opportunities to ask if something is not understood and to have access to implicit knowledge, which may not have been told in an interview. The context of the studies in this dissertation is the participants' life and life situation, which is a different and a more sensitive context requiring other methods. As to a larger extent, PD has moved beyond work-related contexts, methods that use so-called "cultural probes" have been tried

(Crabtree et al., 2003) and have also been used in research of young carers aged 9–17 (Aldridge & Sharpe, 2007). Cultural probes can be said to offer glimpses from within peoples' unique lives (Gaver, Dunne & Pacenti, 1999). They are used by the participants and sent to or collected by the researchers. Cultural probes include maps to highlight important places, postcards with questions to probe attitudes, and cameras to picture things surrounding them (Crabtree et al., 2003). Other studies (Coyle, Doherty, Matthews & Sharry, 2007; Doherty, Coyle & Matthews, 2010) have considered mental health care settings and suggest user participation by proxy (e.g. a therapist). For the purpose of the present studies and for the sake of the group that became our participants, none of these methods were viewed as applicable. We found that the most ethical and effective way to understand the participants' life situation was to use conventional interviews and focus group meetings. In this way no unnecessary intrusions into their lives had to be made and no unnecessary cautious method had to be used.

Data analysis and results

In Studies I and II we chose content analysis, inspired by Krippendorff (2004), to obtain a result that was applicable in the context in which it should be used, i.e. in conjunction with development of a WBSS in a health-related setting. In Study II, Dewey's (1991 [1927]) concept of *public* was used as a way to focus attention on topics that were connected to each group's (the project representatives' and the work group participants'/young carers') social condition. The use of the concept of *public* in that study could be criticized for having been extended too far. However, this was a conscious decision to enable us to evaluate the concept as an analytical concept and mostly in line with how LeDantec et al. (2010) used it. The method yielded results showing interesting differences clearly connected to the different social conditions of the two publics. Study III used grounded theory to be able to follow a process. The analytical process followed the steps described by Corbin and Strauss (2008), comprising line-by-line coding, constant comparison, memo writing and drawing of process diagrams. However, yet another analytical part was included, where data in each sub-category were organized on a timeline. This added input to the analytical effort of elaborating on a possible process.

In all the studies included, data analysis has been thoroughly performed and described. To minimize conceptual overlap between themes/categories, each quotation was given one code only. Codes were revisited during the overall coding process to obtain a similar level of abstraction and to ensure that the codes encompassed the meaning of the quotation. Co-researchers were engaged for discussion of and input to the process of analysis and when

needed to perform an alternate independent analysis (Study III). Once themes/categories had been generated, the codes and their linked quotations were checked for similarities and differences, with the result that some codes were moved. The content of themes/categories was also compared to ensure a sufficient difference between them.

The results have been richly described and each sub-theme or sub-category has been illustrated through interspersed quotations to demonstrate the connection between the data and the themes/categories. Moreover, the applicability of research findings has been clearly demonstrated, showing the relevance of the research.

Ethical considerations

A design project such as the one presented in this dissertation comprises several parts and methods, raising ethical considerations. With regard to ethics, there are two essential principles of concern to this study: to weigh risks against benefits and to monitor participants' autonomy and justice (Ludin, 2011). As a general way to let the participants gain control, they were provided with information about the relevant study on several occasions and were offered the opportunity to ask questions via the phone or e-mail. The information included statements on confidential and secure handling of the material and the right to leave the study at any point without needing to give a reason. A specific context where ethical considerations had to be raised was the interviews in Study I. It was possible that through their questions, the interviewers might invoke difficult and unexpected feelings among the participants. The interviewers all had long work experience in the health care services and felt comfortable performing interviews about sensitive topics. Moreover, at the end of the interview the participants were invited to get in touch if needed. In the focus group interviews, care was taken to provide all participants with an opportunity to talk. It should be remembered that an interview by an interested person individually or with peers in a moderated focus group also has a beneficial side.

The design meetings in Study II did not touch on personal experiences in the same way as the interviews and focus groups did and it was not expected that these meetings would invoke unpleasant feelings. However, on one occasion a participant stayed away from the meeting without notifying anyone. We felt obliged to ask and sent him an e-mail, asking whether anything about the project felt bad and reminding him that he was free to drop out of the study whenever he wanted. The participant responded by e-mailing us that he had had some difficult times and apologised for not turning up. We responded by saying that we were grateful for the work he had done hitherto, stressing the

participants' freedom from obligations, and invited him to proceed when and if he wanted.

Another consideration concerned the degree to which the young persons could be engaged, given their other activities and commitments. This had to be based on ideas of what was reasonable and to ask and listen to what was communicated from them.

To collect data from the participants of Study III (the DT) we chose to perform a focus group interview. As the author of the study was also a member of the DT this choice was a way to methodologically and ethically ensure transparency, i.e. ensuring that every member knew what was being talked about. It is probable that the informants of this study would have felt uneasy, for reasons of loyalty, if they would have declined participation, but declining would have been quite possible. As mentioned above, a focus group may also be beneficial – a way to reflect on the work done 3 years previously. Risk of harm was not expected. The use of e-mail conversations as a second source of data may raise concerns. However, during the design project every participant had read all of these e-mails. To ensure a greater feeling of control it was explicitly stated that the aim of the study was to focus on general processes and not on individuals' actions.

Quotations from the participants are incorporated in the studies to demonstrate the connection between the data and the reported findings. The studies also include Tables with data on the participants and their close others. To ensure confidentiality we have removed personal identifiers, such as street names, the name of a school, etc. In the Tables, we have used less specific terms, such as "parent" and "sibling" instead of "father" and "sister".

Concluding remarks

This dissertation can be understood in at least two ways: (1) as a contribution to our understanding of a WBSS for young carers and of what elements are essential in such a support system; and (2) as an interpretation of PD; a contributor of new views on and insights of design but with inherent barriers to user influence.

Design methods where users are involved, such as PD, can provide knowledge and insights about crucial components in a WBSS. However, it is essential to observe barriers to user influence in the design process. This dissertation takes another view of web-based support, based on young carers' needs. The view of a WBSS as a dissociated unit for "treatment" or "interventions" has been replaced by a view of the WBSS as a mediating tool to connect people with each other and to facilitate their connections to needed

real-life services. Although young carers' need of real-life support may be typical for their group, the literature shows that several other groups in society need structural support more than symptomatic interventions. Furthermore, there are quite consistent findings showing that web-based support is a second-hand choice. The majority of young people (and older people as well) prefer personal real-life support to online support and those who choose online support have special reasons for doing so. This is not supposed to mean that WBSSs are of no use. To make a simplification, it seems that young people with poor mental health are more prone to seek support online compared with those with less poor mental health. Therefore a WBSS could serve as a means to capture them and offer online support, but it could also serve as a tool for them to reach real-life support and services. In this way, WBSSs could act like a life raft, able to capture people who are exhausted and "carry them to land" as it were, like a "bridge over troubled water" (lyrics by Simon & Garfunkel, 1970).

From the perspective of constructed publics, the WBSS will not only be a life saver and a mediating tool, it will also be an artefact able to assemble publics around the issue of young carers, for example. A WBSS is able to convey to its visitors their common ground, making them aware of shared social conditions and helping to connect them with each other. A WBSS may over time also have the potential to influence how society understands an issue, in turn triggering change to practices and policies affecting its members, such as health policies (Mohr, 2004).

Future research

In this new age, great hopes are placed on web-based health solutions. Authorities hope to offer greater availability and at the same time save money. However, as has been shown in this dissertation, use of web-based support could be viewed as a second-hand choice. Similarly, some research has found that online support will, for different reasons, not necessarily reduce human involvement, but may sometimes even increase it. Therefore, it would be of value to investigate the ground for such hopes and to obtain a clearer picture of the process.

The findings of Study III are interesting and may be assumed to be applicable also in contexts other than DTs. What happens, for example, to a therapist's attitude to his or her patients when he/she has to "deliver" more treatments faster? Will the listening process follow the same pattern as in the DT, i.e. that the therapist develops a preference for expert knowledge over the experiences of his or her client? The results need to be corroborated and this might be done in different settings.

Finally, it would be of interest to develop the sketched model of a WBSS. A comprehensive review of existing WBSSs and their way of supporting different user groups could be a starting point.

References

- Ainsworth, M. (1995). ABC's of "internet therapy". E-therapy: history and survey. Retrieved 23 October 2012 at <http://www.metanoia.org/imhs/history.htm> .
- Aldridge, J. (2002). *Young carers and parental mental illness*. Young Carers Research Group. Loughborough: Loughborough University.
- Aldridge, J., Sharpe, D. (2007). *Pictures of young caring*. Leicestershire: Young Carers Research Group.
- Ali L, Ahlström BH, Krevers B, Skärsäter I. (2012). Daily life for young adults who care for a person with mental illness: a qualitative study. *Journal of Psychiatric and Mental Health Nursing*, 19(7), 610–617.
- Andersson, G., Carlbring, P., Berger, T., Almlöv, J., Cuijpers, P. (2009). What makes internet therapy work? *Cognitive Behaviour Therapy*, 38, 55-60.
- Arendt, J., Wagner, C. (2010). Beyond description: converting web site usage statistics into concrete site improvement ideas. *Journal of Web Librarianship*, 4(1), 37-54.
- Arnett, J. (2007). Emerging adulthood: what is it and what is it good for? *Child development perspectives*, 1(2), 68-73.
- Bandura, A. (1977). Self-efficacy: Toward a unifying theory of behavioural change *Psychological Review*, 84(2), 191-215.
- Bandura, A. (1984). Recycling misconceptions of perceived self-efficacy. *Cognitive Therapy and Research*, 8(3), 231-255.
- Banks P, Cogan N, Riddell S. (2002). Does the covert nature of caring prohibit the development of effective services for young carers? *British Journal of Guidance & Counselling*, 30, 229-246.
- Barak, A., Boniel-Nissim, M., Suler, J. (2008). Fostering empowerment in online support groups. *Computers in Human Behaviour*, 24, 1867-1883.
- Barak, A., Hen, L., Boniel-Nissim, M., Shapira, N. (2009). A comprehensive review and a meta-analysis of the effectiveness of internet-based psychotherapeutic interventions. *Journal of Technology*

- in *Human Services*, 26(2/4), 109-160.
- Barak, A., Grohol, J. (2011). Current and future trends in Internet supported mental health interventions. *Journal of Technology in Human Services*, 29, 155-196.
- Beardslee, W., Gladstone, T., Wright, E., Cooper, A. (2003). A family-based approach to the prevention of depressive symptoms in children at risk: Evidence of parental and child change. *Pediatrics*, 112, e119-e131.
- Becker, S.(Ed.). (1995). *Young carers in europe: an exploratory cross-national study in Britain, France, Sweden and Germany*. Leicestershire: Young Carers Research Group.
- Becker, S. (2007). Global perspectives on childrens unpaid caregiving in the family: Research and policy on “Young Carers” in the UK, Australia the USA and Sub-Saharan Africa. *Global Social Policy*, 7(1), 23-50.
- Becker, S., Becker, F. (2008). *Young adult carers in the UK: experiences, needs and services for carers aged 16-22*. London: The Princess Royal Trust for Carers.
- Bélanger, E., Bartletta, G., Dawesb, M., Rodríguez, C., Hasson-Gidonic, I. (2012). Examining the evidence of the impact of health information technology in primary care: An argument for participatory research with health professionals and patients. *International Journal of Medical Informatics*, 81(10), 654-661.
- Bergvall-Kåreborn, B., Ståhlbrost, A. (2008). Participatory design – one step back or two steps forward? *Proceedings of the Tenth Anniversary Conference on Participatory Design 2008*, 102-111. New York: ACM.
- Berkman, L. (1995). The role of social relations in health promotion. *Psychosomatic Medicine*, 57, 245-254.
- Bovier, P., Chamot, E., Perneger, T. (2004). Percieved stress, internal resources, and social support as determinants of mental health among young adults. *Quality of Life Research*, 13, 161-170.
- Brennan P., Ripich, S., Moore, S. (1991). The use of home-based computers to support persons living with AIDS-ARC. *Journal of Community Health Nursing*, 8, 3 -14.
- Bratteteig, T., Wagner, I. (2010). Spaces for Participatory Creativity. *Proceedings of the 11th Biennial Participatory Design Conference*, 51-60. New York: ACM.

- Broddasson, T. (2007). Youth and new media in the new millennium. *Nordicom review*, 27, 105-118.
- Brouwer, W., Kroeze W., Crutzen, R., de Nooijer, J., de Vries, N., Brug, J. et al. (2011). Which intervention characteristics are related to more exposure to internet-delivered healthy lifestyle promotion interventions? A systematic review. *Journal of Medical Internet Research*, 13(1), e2.
- Bucciarelli, L. (1988). An ethnographic perspective on engineering design. *Design Studies*, 9(3), 159-168.
- Buckingham, D. (2010). Do we really need media education 2.0? Teaching in the age of participatory media. K. Drotner & K Shröder (Eds.), In *Digital content creation: perspectives, practices & perspectives*, 287-304. New York: Peter Lang Publishers.
- Butler, A.H., Astbury, G. (2005). The caring child: An evaluative case study of the Cornwall young carers project. *Children & Society*, 19, 292-303.
- Bødker (1996). Creating conditions for participation-conflicts and resources in systems design. *Human Computer Interaction*, 11(3), 215-236.
- Bødker, S., Iversen, O., (2002). Staging a professional participatory design practice - moving PD beyond the initial fascination of user involvement. *Proceedings of NordiCHI, October 19-23*, 11-18, New York: ACM.
- Cajander, Å. (2010). Usability-who cares? The introduction of user centred systems design in organisations [dissertation]. Uppsala, Sweden: Faculty of Science and Technology, University of Uppsala.
- Chang, A., Bordia, P., Duck, J. (2003). Punctuated equilibrium and linear progression: toward a new understanding of group development. *Academy of Management Journal*, 46(1), 106-117.
- Chang, M., Jungnickel, K., Orloff, C., Shklovski, I. (2005). Engaging the city: Public interfaces as civic intermediary. *Proceedings of CHI '05 Extended Abstracts on human Factors in computing systems*, pp. 2109-2110. New York: ACM.
- Cohen, S., McKay, G. (1984). Social support, stress and the buffering hypothesis: a theoretical analysis. In A. Baum, S. Taylor, J. Singer (Eds.) *Handbook of psychology and health*. Hillsdale, NJ: Wiley & Sons.

- Colombotos, J. (1969). Personal versus telephone interviews: effect on responses. *Public Health Reports*, 84(9), 773-782.
- Cooklin, A. (2006). Children as carers of parents with mental illness. *Psychiatry*, 5(1), 32-35.
- Conci, M., Chiara, L. (2010) Not every patient is 2.0: importance of mediation for accessible healthcare services (oral presentation). *The European Association for the Study of Science and Technology (EASST) conference, 2-4 September, Trento, Italy*, p. 534.
- Corbin, J., Strauss, A. (2008) *Basics of qualitative research: Techniques and procedures for developing grounded theory*. Thousand Oaks, US: Sage Publications.
- Coster, S., Norman, I. (2009). Cochrane reviews of educational and self-management interventions to guide nursing practice: a review. *International Journal of Nursing Studies*, 46, 508-528.
- Coyle, D., Doherty, G., Matthews, M., Sharry, J. (2007). Computers in Talk-Based Mental Health Interventions. *Interacting with Computers* 19(4), 545-562.
- Crabtree, A., Hemmings, T., Rodden, T., Cheverst, K., Clarke, K., Dewsbury, G., et al. (2003). Designing with care: Adapting cultural probes to inform design in sensitive settings. *Proceedings of OzCHI*, 4-13. Brisbane: Ergonomics Society of Australia.
- Cross, N., Clayburn-Cross, A. (1995). Observations of teamwork and social processes in design. *Design Studies* 16, 145-170.
- Curtis, B., Walz, D., Elam, J. (1990). Studying the process of software design teams. *Proceedings of the 5th international software process workshop on experience with software process models*, 52 – 53.
- Dalgard, O., Bjørk, S., Tambs, K. (1995). Social support, negative life events and mental health. *The British Journal of Psychiatry*, 166, 29-34.
- Dahlqvist-Jönsson, P., Wijk, H., Danielson, E., Skärsäter, I. (2011), Outcomes of an educational intervention for the family of a person with bipolar disorder: a 2-year follow-up study. *Journal of Psychiatric and Mental Health Nursing*, 18, 333-341
- Danielsson, K., Wiberg, C. (2006). Participatory design of learning media: designing educational computer games with and for teenagers. *Interactive Technology & Smart Education*, 4, 275-292.
- Darses, F., Wolff, M. (2006). How do designers represent to themselves

- the users' needs? *Applied Ergonomics*, 37, 757-764.
- Dearden, C., Becker, S. (2000). *Growing up caring: Vulnerability and transition to adulthood – young carers' experiences*. Leicester: Joseph Rowntree Foundation.
- Dearden, C., Becker, S. (2004). *Young carers in the UK: the 2004 report*. London: Carers UK.
- Dennis, A., Garfield, M., Reinicke, B. (2008). Towards an integrative model of group development. *Sprouts: Working Papers on Information Systems*, 8(3).
- Dewey, J. (1991 [1927]). *The public and its problems* (reprint). Ohio: Swallow Press.
- DiSalvo, C., Maki, J., Martin, N. (2007). MapMover: a case study of design-oriented research into collective expression and constructed publics. *Proceedings of the SIGCHI conference on human factors in computing systems*, 1249-1252.
- DiSalvo, C. (2009). Design and the Construction of Publics. *Design Issues*, 25, 48-63.
- DiSalvo, C., Lodato, T., Fries, L., Schechter, B., Barnwell, T. (2011). The collective articulation of issues as design practice. *CoDesign*, 7(3-4), 185-197.
- Doherty, G., Coyle, D., Matthews, M. (2010). Design and evaluation guidelines for mental health technologies. *Interacting with computers*, 22, 243-252.
- Dorst, K., Cross, N. (2001). Creativity in the design process: co-evolution of problem-solution. *Design Studies*, 22(5), 425-437.
- Dorst, K., Dijkhuis, J. (1995). Comparing paradigms for describing design activity. *Design Studies* 16, 261-274
- Drost, L., Cuijpers, P., Schippers, G. (2011). Developing an interactive website for adolescents with a mentally ill family member. *Clinical Child Psychology and Psychiatry*, 16(3), 351-364.
- Earley, L., Cushway, D., Cassidy, T. (2007). Children's perceptions and experiences of care giving: a focus group study. *Counselling Psychology Quarterly*, 20, 69-80.
- Ebrahim, N., Ahmed, S., Taha Z. (2009). Virtual Teams: a Literature Review. *Australian Journal of Basic and Applied Sciences*, 3(3), 2653-2669.

- Ehn, P. (1988). Playing the language games of design and use: on skill and participation. *Proceedings of the ACM SIGOIS and IEEECS TC-OA conference*, 142-157. New York: ACM.
- Ehn, P. (2008). Participation in Design Things. *Proceedings of Participatory Design Conference, CPSR/ACM*, 92-101. New York: ACM.
- Elf, M., Rystedt, H., Lundin, J., Krevers, B. (2012). Young carers as co-designers of a web-based support system - the views of two publics. *Informatics for Health and Social Care*, 37(4), 203-216.
- Elf, M., Skärsäter, I., Krevers, B. (2011). "The web is not enough, it's a base" – an explorative study of what needs a web-based support system for young carers must meet. *Informatics for Health and Social Care*, 36(4), 206-219.
- Eysenbach, G., Powell, J., Englesakis, M., Rizo, C., Stern, A. (2004). Health-related virtual communities and electronic support groups: Systematic review of the effects of online peer to peer interactions. *British Medical Journal*, 328, 1166-1171.
- Fallman, D. (2003). Design-oriented Human—Computer Interaction. *Proceedings of the SIGCHI conference on Human factors in computing systems*, 225-232. New York: ACM.
- Feenberg, A.L., Licht, J., Kane, K., Moran, K., Smith, R. (1996). The online patient meeting. *Journal of the Neurological Sciences*, 139, 129–131.
- Fiore, S., Salas, E., Cuevas, H., Bowers, C. (2003). Distributed coordination space: toward a theory of distributed team process and performance. *Theoretical Issues in Ergonomics Science*, 4(3-4), 340-364.
- Fisher, G., Giaccardi, E. (2006). Meta-design: A framework for the future of end-user development. H. Lieberman, F. Paternó, V. Wulf (Eds.) In *End user development*, 427-459. Dordrecht, NL: Springer.
- Fleicher, L., Kandadai, V., Keenan, E., Miller, S., Devarajan, K., Ruth, K. et al. (2012). Build it, and will they come? Unexpected findings from a study on a web-based intervention to improve colorectal cancer screening. *Journal of Health Communication*, 17, 41-53.
- Flicker, S., Maley, O., Ridgley, A., Biscope, S., Lombardo, C., Skinner, H. (2008). e-PAR: using technology and participatory action research to engage youth in health promotion. *Action Research*, 6(3), 285-303.

- Freeman, E., Barker, C., Pistrang, N. (2008). Outcome of an online mutual support group for college students with psychological problems. *Cyberpsychology & Behavior*, 11, 591-593.
- Galegher, J., Sproull, L., Kiesler, S. (1998). Legitimacy, authority, and community in electronic support groups. *Written Communication*, 15, 493-530.
- Gaver, W., Dunne, A., Pacenti, E. (1999). Cultural Probes. *Interactions*, 6(1), 21-29.
- Gersick, C. (1988). Time and transitions in work teams: toward a new model of group development. *Academy of Management Journal*, 31(1), 9-41.
- Giesbers, J., Verdonck-de Leeuw, I., van Zuuren, F., Kleverlaan, N., van der Linden, M. (2010). Coping with parental cancer: web-based peer support in children. *Psycho-Oncology*, 19, 887-892.
- Gould, J., Lewis, C. (1985). Designing for usability: key principles and what designers think. *Communication of the ACM*, 28, 300-311.
- Gould, M., Munfakh, J., Lubell, K., Kleinman, M., Parker, S. (2002). Seeking Help From the Internet During Adolescence. *Journal of American Academy of Child & Adolescent Psychiatry*, 41(10), 1182-1189.
- Graneheim, U., Lundman, B. (2004). *Nurse education today*, 24, 105-112.
- Grant, G., Repper, J., Nolan, M. (2008). Young people supporting parents with mental health problems: experiences of assessment and support. *Health and Social Care in the Community*, 16(3), 271-281.
- Grey, B., Robinson, C., Seddon D. (2007). Invisible Children: Young Carers of Parents with Mental Health Problems - The Perspectives of Professionals. *Child and Adolescent Mental Health*, 13, 160-172.
- Griffiths, K., Caelear, A., Banfield, M., Tam A. (2009). Systematic review on Internet Support Groups (ISGs) and Depression (1): do ISGs reduce depressive symptoms? *Journal of Medical Internet Research*, 11, e41.
- Grudin, J. (1993). Grudin, J. (1993). Obstacles to participatory design in large product development organizations. In D. Schuler and A. Namioka (Eds.), *Participatory design: principles and practices* (pp. 99-119). Hillsdale, New Jersey: Erlbaum.
- Guindon, R. (1990). Designing the design process: exploiting opportunistic thoughts. *Human-Computer Interaction*, 5(2), 305-344.

- Halloran, J., Hornecker, E., Fitzpatrick, G., Weal, M., Millard, D., Michaelides, D. et al. (2006). Unfolding Understandings: Co-designing UbiComp In Situ, Over Time. *Proceedings of DIS 2006, June 26-28*, 109-118. New York: ACM.
- Hasan, L. Morris, A., Proberts, S. (2009). Using google analytics to evaluate the usability of e-commerce sites. M. Kurosu (Ed.) In *Human Centred Design, HCII 2009*, 697-706. Heidelberg: Springer Verlag.
- Hefner, J., Eisenberg, D. (2009). Social support and mental health among college students. *American Journal of Orthopsychiatry*, 79, 491-499.
- Hevner, A., March, S., Park, J., Ram, S. (2004). *Design science in information systems research*. *MIS Quarterly*, 28(1), 75-105.
- Holland, S., Renold, E., Ross, N., Hillman, A. (2010). Power, agency and participatory agendas: a critical exploration of young people's engagement in participative qualitative research. *Childhood*, 17(3), 360-375.
- Horgan, À., Sweeney, J. (2010). Young students' use of the Internet for mental health information and support. *Journal of Psychiatric and Mental Health Nursing*, 17, 117-123.
- James, A. (2007). Principles of youth participation in mental health services. *eMJA of Australia*, 187(7), S57-S60.
- Jenkins, H. (2009). *Confronting the challenges of participatory culture: media education for the 21st century*. (MacArthur foundation reports on digital media and learning). Massachusetts: MIT Press.
- Jordan J., Osbourne, R. (2007). Chronic disease self-management education programs: challenges ahead. *Medical Journal of Australia*, 186, 84-87.
- Kanstrup, A., Glaseman, M., Nielsby, O. (2010). IT-services for everyday life with diabetes: learning design, community design, inclusive design. *Proceedings of DIS 2010, August 16-20*, 404-407. New York: ACM.
- Kaptelinin, V., Nardi, B. (2006). *Acting with technology: activity theory and interaction design*. Cambridge, Massachusetts: MIT Press.
- Karasti, H. (2010). Taking PD to multiple contexts - a response to Kyng. *Scandinavian Journal of Information Systems*, 22(1), 85-92.
- Koschmann, T. (1996). *Paradigm shifts and instructional technology: an introduction*. In T. Koschmann (Ed.), *CSCL: Theory and practice of an emerging paradigm: computers, cognition, and work*. (pp. 1-23).

- Hillsdale, UK: Lawrence Erlbaum Associates Inc.
- Krippendorff, Klaus (2004). *Content Analysis: An introduction to its methodology*. California: Sage Publications.
- Kujala, S. (2003). User involvement: a review of the benefits and challenges. *Behaviour & Information Technology*, 22(1), 1-16.
- Kummervold, P., Gammon, D., Bergvik, S., Johnsen, J., Hasvold, T., Rosenvinge, J. (2002). Social support in a wired world: use of online mental health forums in Norway. *Nordic Journal of Psychiatry*, 56, 59-65.
- Kuniavsky, M. (2003). *Observing the user experience*. San Fransisco: Morgan Kaufmann Publishers.
- Larsson, A. (2003). Making sense of collaboration: the challenge of thinking together in global design teams. Proceedings of the 2003 international ACM SIGGROUP conference on supporting group work, 153-160. New york: ACM.
- Lave, J., Wenger, E. (1991). *Situated learning: legitimate peripheral participation*. Cambridge: Cambridge University Press.
- Le Dantec, C., Christensen, J., Bailey, M., Farrell, R., Ellis, J., Danis, C., et al. (2010). A Tale of Two Publics: Democratizing Design at the Margins. *Proceedings of DIS 2010, August 16-20, Aarhus*, 11-20. New York: ACM.
- Lee, T., King, W. (1991). The effect of user participation on system success: towards a contingency theory of user satisfaction. *Proceedings of the International Conference on Information Systems, New York, NY*, 327-338.
- Li, J., Wilson, L., Stapleton, S., Cregan, P. (2006). Design of an advanced telemedicine system for emergency care. *Proceedings of the 18th Australia conference on computer-human interaction: design-activities, artefacts and environments*, 413-416.
- Light, A. (2010). The unit of analysis in understanding the politics of participatory practice. *Proceedings of the 11th biennial participatory design conference*, 183-186.
- Lindquist, S. (2007). *Perspectives on cooperative design* [dissertation]. Stockholm, Sweden: NADA, Kungliga tekniska högskolan.
- Lombardo, T. (1987). *The reciprocity of perceiver and environment. The evolution of James J Gibson's ecological psychology*. Hillsdale, NJ, US: Lawrence Erlbaum Associates.

- Lorig, K., Halsted, H. (2003). Self-management education: history, definition, outcomes, and mechanisms. *Annals of behavioural medicine*, 26, 1-7.
- Luck, R. (2007). Using artefacts to mediate understanding in design conversations. *Building Research & Information*, 35(1), 28-41.
- Ludin, Z. (2011). On ethical problem solving in user- centred research: an analysis. *Proceedings of CHI 2011 May 7-12*, 791-798. New York: ACM.
- Maher, M., Bilda, Z., Gül, L. (2006). Impact of collaborative virtual environments on design behaviour. *Design Computing and Cognition*, 305-321.
- Majid, R., Noor, N., Wan Adnan, W., Mansor, S. (2010). A survey on user involvement in software development life cycle from practitioner's perspectives. *Proceedings of Computer Sciences and Convergence Information Technology (ICCIT), 5th International Conference*, 240-243.
- Marcus, M., Estra, H., Eastwood, J., Barnes, K. (2012). What are young people saying about mental health? An analysis of internet blogs. *Journal of Medical Internet Research*, 14(1), e17.
- Markussen, R. (1996). Politics of intervention in design: feminist reflections on the Scandinavian tradition. *AI & Society*, 10, 127-141.
- Marres, N. (2007). The issues deserve more credit: Pragmatist contributions to the study of public involvement in controversy. *Social Studies of Science* 37(5), 759-780.
- Matthews, B., Heinemann, T. (2012). Analysing conversation: studying design as social action. *Design Studies*. Doi: 10.1016/j.destud.2012.06.008.
- Mazzone, E., Read, J., Beale, R. (2008). Design with and for disaffected teenagers. In: *Proceedings of Nordichi*, 290-297, New York: ACM.
- Mohr, W. (2004). Surfacing the life phases of a mental health support group. *Qualitative Health Research*, 14(1), 61-77.
- Nardi, B., Engeström, Y. (1999). A web on the wind: the structure of invisible work. *Computer Supported Cooperative Work* 8, 1-8.
- Nationell psykiatrisamordning och socialstyrelsen. (2007). *Nationell kartläggning – stöd till barn vars föräldrar har kontakt med psykiatri*. Delrapport till "Barn till föräldrar med psykisk sjukdom" (National survey – support for children of parents in contact with

- psychiatry. Interim report to “Children of parents with mental illness”, in Swedish). Stockholm: Socialstyrelsen. Retrieved 22 September 2011 at http://www.socialstyrelsen.se/psykisk_halsa/nationellpsykiatrisamordning2005-2007/Documents/R38Breadsless_Delrapport_Barn till foraldrarmed psykisksjukdom22.pdf.
- Nielsen, J. (2001). *Användbar webbdesign* (Designing web usability) [in Swedish]. Stockholm: Liber AB.
- Nielsen, J. (2006). Participation Inequality: Encouraging More Users to Contribute. Jakob Nielsen's Alertbox. Retrieved 13 December 2012 at http://www.useit.com/alertbox/participation_inequality.html
- Newman, T. (2002). “Young carers” and disabled parents: time for a change of direction? *Disability & Society*, 17, 613-625.
- Nordfeldt, S., Hanberger, L., Berterö, C. (2010). Patient and parent views on a Web 2.0 diabetes portal – the management tool, the generator, and the gatekeeper: qualitative study. *Journal of Medical Internet Research*, 12, e17, 1–15.
- Norcross, J., Wampold, B. (2011). What works for whom: Tailoring psychotherapy to the person. *Journal of clinical psychology*, 67(2), 127–132.
- Novick, G. (2008). Is there a bias against telephone interviews in qualitative research? *Research in Nursing and Health*, 31(4), 391-398.
- O'Reilly, T. (2007). What Is Web 2.0: Design patterns and business models for the next generation of software. *Communication & Strategies*, 65(1), 17-37.
- Owen, J., Goldstein, M., Lee, J., Breen, N., Rowlan, J. (2010). Use of health-related online support groups: population data from the California health interview survey complementary and alternative medicine study. *Journal of Computer-Mediated Communication* 15, 427–446.
- Pacifici, C., White, L., Cummings, K., Nelson, C. (2005). Vstreet.com: a web-based community for at-risk teens. *Child Wellfare*, 84, 25-46.
- Pakenham, K., Chiu, J., Bursnall, S., Cannon, T., Okochi, M. (2006). The psychosocial impact of caregiving on young people who have a parent with an illness or disability: comparisons between young caregivers and noncaregivers. *Rehabilitation Psychology*, 51, 113-126.
- Pakenham, K., Chiu, J., Bursnall, S., Cannon, T. (2007). Relations

- between social support, appraisal and coping and both positive and negative outcomes in young carers. *Journal of Health Psychology*, 12, 89-102.
- Palzkill-Woelfer, J., Hendry, D. (2009). Stabilizing homeless young people with information and place. *Journal of the American Society for Information Science and Technology*, 60(11), 2300–2312.
- Paulos, E., Jenkins, T. (2005). Urban probes: encountering our emerging urban atmosphere. Proceedings of the SIGCHI Conference on Human Factors in Computing Systems, pp. 341-350 New York: ACM.
- Peeters, M., Van Tuijl, H., Reymen, I. and Rutte C. (2007). The development of a design behaviour questionnaire for multidisciplinary teams. *Design Studies* 28, 623-643.
- Percy-Smith, B. (2007). ‘You think you know? You have no idea’: youth participation in health policy development. *Health Education Research*, 2(6), 879-894.
- Picket-Schenk, S., Lippincott, R., Bennett, C., Steigman, P. (2008). Improving knowledge about mental illness through family-led education: the Journey of Hope. *Psychiatric Services*, 2008, 59, 49–56.
- Pinquart, M., Sörensen, S. (2003). Differences between caregivers and non-caregivers in psychological health and physical health: a meta-analysis. *Psychology and Aging*, 18(2), 250-267.
- Poole, M. (1983). Decision development in small groups, III: A multiple sequence model of group decision development. *Communication monographs*, 50(4), 321-341.
- Postmes, T., Spears, R., Lea, M. (1998). Breaching or Building Social Boundaries? SIDE-Effects of Computer-Mediated Communication. *Communication Research*, 25(6), 689-715.
- Postmes, T., Brunsting, S. (2002). Collective action in the age of the Internet: Mass communication and online mobilization. *Social Science Computer Review*, 20(3), 290-301.
- Reblin M and Uchino B. (2008). Social and emotional support and its implication for health. *Current Opinion in Psychiatry*, 21, 201-205.
- Redström, J. (2008). Re: Definitions of use. *Design Studies*, 29, 410-423.
- Reicher, S.D., Spears, R., Postmes, T. (1995). A Social identity model of deindividuation phenomena, *European Review of Social Psychology*, 6(1), 161-198.

- Remy Dodin. (2009). Réseaux et tivoli mainframe – REXX eCS. AVxCAT – Audio/Video eXtended Conversion and Authoring Tool. Retrieved 26 February 2011 at <http://remydodin.levillage.org/avxcat.html>.
- Renahy, E., Parizot, I., Chauvin, P. (2010). Determinants of the frequency of online health information seeking: results of a web-based survey conducted in France in 2007. *Informatics for Health & Social Care January*, 35, 25–39.
- Reupert, AE., Maybery, D. (2010). “Knowledge is power”: educating children about their parent's mental illness. *Social Work in Health Care*, 49(7), 630-646.
- Rith, C., Dubberly, H. (2006). Why Horst Rittel matters. *Design Issues*, 22(4), 1-20.
- Robinson, M. (2012). How design engineers spend their time: job content and task satisfaction. *Design Studies* 33, 391-425.
- Rocco, E. (1998). Trust breaks down in electronic contexts but can be repaired by some initial face-to-face contact. *Proceedings of CSCW '98, Seattle WA, November*, 501-529. New York: ACM.
- Rystedt, H., Säljö, R. (Eds.) (2008). Kunskap och människans redskap: teknik och lärande (Knowledge and human tools: technology and learning) [in Swedish]. Lund: Studentlitteratur.
- Sandell, R. (2004). Teknik eller relation? Kritiska faktorer i psykoterapi (Technic or relationship? Critical factors in psychotherapy) [in Swedish]. *Läkartidningen*, 101, 1418-1422.
- Saarijärvi, T., Sääksjärvi, M. (1990). The missing concepts of user participation: an empirical assessment of user participation and information system success. *Scandinavian Journal of Information Systems*, 2, 25-42.
- Sanoff, H. (2007). Multiple views of participatory design (originally published 2006). *International Journal of Architectural Research*, 2, 56-79.
- Schultz R., Sherwood P. (2008). Physical and mental health effects of family caregiving. *American Journal of Nursing*, 108, 23-27.
- Schön, D. (1992). Designing as a reflective conversation with the materials of a design situation. *Knowledge Based Systems*, 5(1), 3-14.
- Science Plus. (2010). Software for science [Internet]. *Atlas.ti*. Retrieved 21 June 2010 at <http://www.scienceplus.com/atlasti/>.

- SFS 1982:763. *Hälso- och sjukvårdslagen, §2g. [Health care law, §2g]* Stockholm: Riksdagen.
- Shandley, K., Austin, D., Klein, B., Kyrios, M. (2010). An evaluation of 'Reach Out Central': an online gaming program for supporting the mental health of young people. *Health Education Research*, 25(4), 563-574.
- Simon, H (1996). *The sciences of the artificial* (3rd ed.). Massachussets: MIT-press.
- Sjöberg, C., Timpka, T. (1998). Participatory design of information systems in health care. *Journal of the American Medical Informatics Association*, 5(2), 177-183.
- Skärsäter, I., Ali, L., Elf, M., Krevers, B. (2011). Young adult carers in the risk zone. Design of a health-promoting, randomized two-armed controlled trial for young adults who support people with mental illness. *Medicine 2.0 Congress, Sept 17-18 2011*, Stanford, US. Poster presentation, p. 18.
- Sluis-Thiescheffer (2007). How to optimize early design methods with children? *Proceedings of the 6th international conference on Interaction design and children*, 17-24. New York: ACM.
- Sonck, N., Livingstone, S., Kuiper, E., de Haan, J.(2009). Digital Literacy and Safety Skills. London: EU kids online. Retrieved 26 July 2012 at <http://eprints.lse.ac.uk/33733/1/Digital%20literacy%20and%20safety%20skills%20%28lsero%29.pdf>
- SOU 2006:77. *Ungdomar, stress och psykisk ohälsa: analys och förslag till åtgärder* (Youth, stress and mental health problems: analysis and suggestions for action) [in Swedish]. Stockholm: Fritzes.
- Spinuzzi, C. (2002). A Scandinavian challenge, a US response: methodological assumption I Scandinavian and US prototyping approaches. *Proceedings of the 20th annual international conference on Computer documentation*, 208-215. New York: ACM.
- Spinuzzi, C. (2005). The methodology of participatory design. *Technical Communication*, 52(2), 163-174.
- Star, S.L., Griesemer, J. (1989). Institutional ecology, 'translations' and boundary objects: Amateurs and professionals in Berkeley's museum of vertebrate zoology, 1907-39. *Social studies of science*, 19(3), 387-420.

- Steen, M. (2011). Tensions in human-centred design. *CoDesign*, 7(1), 45-60.
- Stempfle, J., Badke-Schaub, P. (2002). Thinking in design teams – an analysis of team communication. *Design Studies*, 23, 473-496.
- Stinson, J., Toomey, P., Stevens, B., Kagan, S., Duffy, C., Huber, A., Malleson, P. et al. (2008). Asking the experts: exploring the self-management needs of adolescents with arthritis. *Arthritis & Rheumatism*, 59, 65-72.
- Stinson, J., Wilson, R., Gill, N. (2009). A systematic review of internet-based self-management interventions for youth with health conditions. *Journal of Pediatric Psychology*, 34, 495–510.
- Stoltz, P., Skärsäter, I., Willman, A. (2009). “Insufficient evidence of effectiveness” is not “evidence of no effectiveness:” evaluating computer-based education for patients with severe mental illness. *Worldviews on Evidence-Based Nursing*, 6(4), 190-199.
- Säljö, Roger (2006). Lärande och kulturella redskap: om läroprocesser och det kollektiva minnet (Learning and cultural tools: learning processes and collective memory) [in Swedish]. Stockholm: Nordstedts Akademiska Förlag.
- Tajfel, H. (1982). Social psychology of intergroup relations. *Annual Review of Psychology*, 33, 1-39.
- Tanis, M., Postmes, T. (2007). Two faces of anonymity: paradoxical effects of cues to identity in CMC. *Computers in Human Behaviour*, 23, 955-970.
- Thomas, N., Stainton, T., Jackson, S., Cheung, W.Y., Doubtfire, S., Webb, A. (2003). “Your friends don't understand” - Invisibility and unmet need in the lives of “young carers”. *Child and Family Social Work*, 8, 35-46.
- Tuckman, B. (1965). Developmental sequence in small groups. *Psychological Bulletin*, 63(6), 384-399.
- Tuckman, B., Jensen, M. (1977). Stages of small-group development revisited. *Group & Organization Studies*, 2(4), 419-427.
- Tursunovic, M. (2002). Fokusgruppsintervjuer i teori och praktik (Focus groups in theory and practice) [in Swedish]. *Sociologisk forskning*, 1, 63-89.

- Törpel, B. (2005). Participatory Design: A multi-voiced effort. *Proceedings of the 4th decennial conference on Critical computing*, 177-181. New York: ACM.
- Van Uden-Kraan, C., Drossaert, C., Taal, E., Smit, W., Bernelot Moens, H., Van de Laar, M. (2011). Determinants of engagements in face-to-face and online patient support groups. *Journal of Medical Internet Research*, 13(4), e106.
- Vredenburg, K., Mao, J-Y., Smith, P., and Carey, T. (2002). A Survey of User-Centered Design Practice. *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems*, 471-478. New York: ACM.
- Vygotsky, L. (1978). *Mind in society: the development of higher psychological processes*. Eds: M Cole, V John-Steiner, S Scribner, E Souberman. Cambridge, Massachussets: Harvard University Press.
- Wenger E. (1998). *Communities of practice: learning, meaning and identity*. Cambridge: Cambridge University Press.
- Westerlund, B. (2005). Design space conceptual tool - grasping the design process. *Proceedings of Nordes, the Nordic Design Research Conference, 'In the Making', Nordes, Copenhagen, May 29–31*. Retrieved 7 August 2012 at <http://urn.kb.se/resolve?urn=urn:nbn:se:kth:diva-11253>.
- Wilkinson, S. (2007). Focus Groups. In J. Smith (Ed), *Qualitative psychology: a practical guide to research methods*. London: Sage Publications Limited.
- Wodzicki, K., Schwämmlein, E., Cress, U., Kimmerle, J. (2011) Does the type of anonymity matter? the impact of visualization on information sharing in online groups. *Cyberpsychology, Behavior, and Social Networking*, 14(3), 157-160.
- World Internet Institute (2010). *Svenskarna och internet 2009. (The Swedes and the Internet 2009)* [in Swedish]. Hudiksvall: World Internet Institute.
- Ybarra, M., Alexander, C., Mitchell, K. (2005). Depressive symptomatology, youth internet use, and online interactions: a national survey. *Journal of Adolescent Health*, 36, 9-18.
- Ybarra, M., Suman, M. (2006). Help seeking behaviour and the Internet: a national survey. *International Journal of Medical Informatics*, 75, 29-41.

Östman, M. (2000). *Family burden and participation in care. A study of relatives to patients admitted to voluntary and compulsory psychiatric care*. Diss. Lunds Universitet.