DESIGNING ONLINE SUPPORT FOR FAMILIES LIVING WITH DEPRESSION
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“When it is dark enough you can see the stars.”
Ralph Waldo Emerson

Unexpectedly, my close friend and working partner decided to take his life on a Sunday in March 2009. We worked together on the website in the present project. Prior to starting this project, I was convinced that families whose daily life is marked by depression need support. This conviction was only strengthened by the recent events in my own life. Paradoxically and ironically, I eventually became a member of the target group of the present thesis. I am extremely thankful to the people around me that supported me and kept me afloat through my grief. Luckily, and in an unplanned manner, I was fortunate to meet persons on the way that helped me cope. Regrettably, many of the reports in the present thesis, showing the lack of support to families living with depression and its consequences, were confirmed by my experiences. In spite of legal involvement from an early point – the police was in place shortly after my friend’s death – and the health care system’s early presence in connection with organ donation, I wasn’t offered any kind of help through these channels. There was further involvement with different official organizations, but not at any point was I offered any professional support from the above mentioned channels. I was in contact with a few empathic persons at occasions, which certainly helped. However, I was left alone in a crisis.

Willpower, support from people around me and the conviction that the target group of this thesis is in need of attention and support from professionals have helped me overcome the difficulty to attend to this project, which I worked on with the cooperation of my late friend. I did not want this project, and whatever good I hope can come out of it, to have been done in vain. This event was however not decisive in my choice of research subject. It happened after completion of the three first papers (papers I-III) and of the data collection and most parts of the analysis of the last two papers (papers IV-V) in the present thesis. I wish to express my greatest respect to those participants that made this project possible. I admire them for their strength, their courage and their energy to share their innermost thoughts and feelings with me. I can also see how altruism and the wish to help others in a similar situation can motivate a person to share his or her story. A good purpose may help give a meaning to something that seems and feels so flagrantly meaningless.
I have been reticent to speak about this event for different reasons. One of them is the wish not to linger in this tragic event. I do not want the rest of my life nor my identity or my encounters with others to be focused around this tragedy. This is the dark side of life. It is now indelibly part of me. Another fear is the contagiousness of suicide in society – how can one raise awareness, help an often invisible group, and balance the pros and cons of talking about suicide without influencing already suicidal minds? Yet, the wish to experience and enjoy life from its bright side is stronger than ever. I am also persuaded that an experience like this needs to be talked about. It cannot be dealt with in silence without further consequences. My hope is that the revelation of these happenings can be a miniature step in fighting the stigma around the subjects of mental illness and suicide.

I dedicate this work to life.
INNEHÅLL

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Families living with mental illness experience an added burden and may experience such psychological distress that they require therapeutic intervention. The Internet is used as a daily tool by a growing share of the population worldwide, including for health related matters. Its potential as a health care tool, including advantages and drawbacks, should be explored.

The overall aim of the present thesis was to explore the relatives’ experiences of living close to a person with depression and the Internet’s potential to address their needs. Explorative qualitative research has been used to map the e-health field in relation to depression, to explore what the Internet offers the families living with depression, as well as the relatives’ experiences of living with a person with depression. An iterative design process was used in the development of a digitally based tool aimed at supporting the relatives in their daily life with depression. Users’ experiences of the tool were explored using qualitative explorative research.

A vast array of different organizations and initiatives are represented within the e-health field. However, initiatives that are targeted and tailor-made for families living with depression are scarce. Research in the e-health field with focus on depression illuminates health seekers’ and online community users’ profiles, effects of online cognitive behavioral therapy (CBT), and a number of strengths (i.e. accessibility) and weaknesses (i.e. reliability) related to the Internet as a health care tool.

Living close to a person with depression can strongly affect the private, social and professional areas of the relatives’ daily life. A growing feeling of not living one’s own life may arise, due to the difficulties of balancing relationships, a process of adaptation and re-evaluation of life circumstances, and a struggle to act as advocate and voice for the person with depression within the health care system and society. Relatives often come in contact with health professionals on
behalf of their ill kin and need information and support; needs that are rarely addressed by the health care system.

A digitally based tool aimed at supporting the relatives in their daily life with depression was developed using an iterative design process. The tool’s development was carried out in close cooperation with users with the help of focus groups and prototypes. Motivations and obstacles to using online self-help tools were illuminated. Privacy stood out as an important factor when developing online tools. The study resulted in a website, www.sommarregn.se, entailing an online diary (private and encrypted), including scales, and a forum (members only access), including an e-mail function.

Users’ experiences of the website over a 10 weeks test period were illuminated. The diary and forum appeared to fill a number of valuable functions, although a further development of the tool may enhance its usability, which was good. The tool promoted communication with the self and others. The Internet as a technology offered a number of advantages, such as convenience of use and perceived anonymity, and disadvantages, such as qualitative issues.

The relatives’ needs ought to be addressed in order to support them in a daily life with depression. Empowered relatives are in a better position to help their ill kin and support may prevent ill health in the relatives themselves, and subsequently additional costs to society. Health care professionals meet patients that are also online health seekers. Professionals must be aware of the advantages and drawbacks of e-health when meeting patients. In an economically pressured society, alternative support options have to be explored in order to address the needs of target groups at risk.
ORI G I NAL PAPERS I-IV


IV. Stjernswärd S, Östman M, Löwgren J. A design study of motivations and obstacles for relatives of persons with depression to use online self-help tools. *Submitted*.

V. Stjernswärd S, Östman M. Illuminating user experiences of a website for the relatives of persons with depression. *Submitted*.

All papers have been reprinted with permission from the publishers. The data collection and analysis for all papers were carried out by the first author, except for the fifth study’s data collection (paper V), which was carried out by the second author. The manuscripts were written with support from the co-authors.
INTRODUCTION

A researcher always approaches a project with his/her attitudes, emotions, judgments and values (Busfield, in Slade and Priebe 2006), making true objectivity hardly possible. Most people have prejudices, consciously or not. A researcher can only with difficulty separate him- or herself from his or her preunderstanding, however it can be made conscious through questioning and reflection; methods that were practiced throughout the course of the current research process. Writing a thesis requires time, energy and resources. A special interest in the subject of study is naturally a great advantage and motivator.

When undertaking the present project, the main interests were in exploring how the Internet can be used as a health care tool and how relatives are affected by the presence of an illness within the family. Previous experiences raised awareness about the possible and sometimes devastating consequences for families when an illness or accident strikes one of its members. There was an interest in learning more about how depression affects family dynamics, the illness being so common and estimated to become the second cause of disability adjusted life years (DALY) by 2020 (World Health Organization 2001). Mental illness is also subject of taboos and fascinating in view of different cultural perspectives, making it an interesting research subject.

Depression is unfortunately common, but fear of stigma, among others, makes it a private matter that is kept silent. Working with this project has led to an enhanced consciousness of the high frequency of depression and of persons somehow affected by the illness. This knowledge spurred the undertaking and completion of this project and reinforces the importance of acknowledging and supporting families living with mental illness. On the one hand to offer them relevant information and support, on the other hand to help them assist their ill kin, for instance by seeking appropriate professional help. Attending to symptoms of depression at an early stage may help prevent a worsening of the condition and also spare families from a lot of suffering. Hopefully, this thesis helps bring light onto the relatives’ experiences and their needs when daily life is colored by mental illness.
BACKGROUND

Depression
Depression is a major and global health problem, affecting approximately 121 million people worldwide and representing one of the leading causes of disability worldwide (World Health Organization Jul. 2009). Depression is estimated to rank as the second leading cause of Disability Adjusted Life Years (DALY) by 2020, calculated for both sexes and in the age category 15-44 years (World Health Organization 2001). The lifetime prevalence for major depression is estimated at 10-13% for men and 21-24% for women (Kessler et al. 1994; Kringlen et al. 2001). Depression occurs in higher frequencies among women and increasing frequencies among older age groups (Socialstyrelsen 2005) and young people (Kessler and Walters 1998; Socialstyrelsen 2005). Depression can be treated effectively in primary care, with pharmacological treatment and psychotherapy. Depression can have a lethal outcome and losses to suicide are estimated at 877 000 persons per year (World Health Organization 2003). As an average for 53 countries for which complete data is available, the age-standardized suicide rate for 1996 was 15.1 per 100 000, with rates of 24.0 per 100 000 for males and 6.8 per 100 000 for females (World Health Organization 2001). Suicide is a prominent cause of death among young people (10-24 years of age), standing for 6% of the 2.6 million deaths among young people in 2004 (Patton et al. 2009). Approximately 1200 persons commit suicide in Sweden every year and about half of them have had contact with the health care system within a month prior to their death (Socialstyrelsen Sept. 2009). Stigma related to mental disorders and the lack of resources, including the lack of trained providers are barriers to treatment (World Health Organization 2001; Sirey 2001). Although only estimates, these figures point to a global health problem and societal economic burden that need the health community’s attention and efforts to address them.
According to a calculus from 1997 by the Swedish Institute for Health Economics, the total costs induced directly and indirectly by depression were estimated to approximately 10 billion SEK (Norinder et al. 2000). This figure included estimated direct costs related to depression, indirect costs related to severe depressions that are difficult to treat, and society’s yearly costs and effects of three antidepressive medications. The yearly treatment costs were calculated for care of outpatients, inpatients, medication, sick-leaves, early retirement and mortality. This figure thus excludes costs connected to the patients’ families; for instance costs that can arise due to absence from work in order to attend to the ill person’s needs and sick-leaves due to the added burden and there from originating health problems. Only 10% of the total health care costs in Sweden are dedicated to mental ill health, including costs for therapy (Soback, in Hallerstedt 2006). The available resources for a person suffering from mental illness are primarily his/her social network, including family, friends and colleagues, as well as school, child care and sometimes social services for children, and not only health care services, which are lacking (Soback, in Hallerstedt 2006).

Families Living with Mental Illness
Depression not only affects the depressed person, but also his or her closest network, such as family, friends and colleagues. The family dynamics are influenced by the illness’ presence. Throughout the development of psychiatric care, families have come to play an increasingly important caregiving role, which has affected their lives and needs in many ways. Since the fifties, studies have been carried out about family members’ experiences with mental illness, as summarized in the studies of for instance Jones (2002) and Östman (2000). These studies show that family members’ needs of information and support are not being met successfully. It is important that health care professionals recognise and acknowledge these needs and offer support to families. Family members can be empowered to recognise signs of depression, learn how to act and where to seek support when called for. More knowledge and awareness of families’ experiences and needs may help plan interventions and tools that may support the relatives.

The family often becomes a source of caregiving when a family member becomes ill and may be a decisive factor in determining whether the ill person should be institutionalized or not (Cox 2003). All members may contribute to caregiving, but the mother is often seen as the person responsible for health related issues in the family (Litman 1974; Finley 1989). Spouses and adult children provide most care (80-90%) for the elderly in the family (Brody 1985), but more recent
studies show an increase in the number of caregivers with multiple caregiving responsibilities (Brody 1995). Caregiving for a mentally ill family member affects families in numerous ways and may entail contacts with the hospital and other institutions outside the family (Cox 2003). The health care system has been identified as a source of stress (Rose 1996), with relatives experiencing the need for support and information (Fadden and Kuipers 1987; Jones 2002).

Previous research has shown that families living with mental illness are markedly affected by the illness (i.e. Lefley 1989; Östman and Hansson 2002), but focus has mainly been on schizophrenia and psychoses. Different conceptual frames have derived from this research, such as the family caregiving burden model, the expressed emotion framework, the family stress and coping model, as well as the resiliency model (Rungreangkulki and Gillis 2000). However, there are also a number of studies with special focus on affective disorders, where depression is included (Fadden and Kuipers 1987; Badger 1996b; Karp and Tanarugsachock 2000). Nevertheless, more research in the area of mental illness and family members' experiences has been wished for (Rose 1996). Being a close relative to an ill individual and living with him/her has been identified as an important factor influencing the experience of burden (Östman et al. 2005). Further, relatives of patients from different diagnostic subgroups (psychoses, affective disorders, other diagnoses) were differentiated in one aspect of burden only: spouses of patients with affective disorders had to give up leisure time more often than other relatives in other diagnostic subgroups. Among the subgroups of relatives, spouses showed more burdens and often experienced sufficient participation in treatment, as compared to siblings that more seldom experienced burdens and more seldom felt that their own needs of support had been met by psychiatric services. Furthermore, spouses also had a more positive image of the quality of psychiatric services.

Fadden and Kuipers (1987) found that family members living with a patient having an episode of depression experience a great burden. Living with a kin in an acute episode of mental illness is a risk factor for poor family functioning (Friedmann 1997). Negative symptoms of depression (i.e. hopelessness, irritability) appear to be the most disturbing aspects affecting the experience of burden (Badger 1996a; Coyne et al. 1987), resulting in difficulties in family functioning that sometimes remain unresolved at remission (Badger 1996a; Krantz and Moos 1987). A study of the relationship between coping strategies and family burden among relatives of admitted psychiatric patients showed that there were no significant differences in coping strategies between relatives and a Swedish normative sample (Östman and Hansson 2001). However, the
study showed that relatives seem to use problem solving strategies more often when the situation is amenable to change and emotion focused strategies when the situation is chronic and not expected to change. The authors suggest that qualitative methods based on case studies may increase the knowledge of how relatives appraise their situation and cope.

Including Families and Significant Others in Care
Education to family members is one of the World Health Organization’s (WHO) objectives in addressing depression (World Health Organization 2001). So far, interventions aimed at the family have generally focused on education and sustaining social networks. A number of points characterize good cooperation with relatives, namely considering the relatives as a resource that should be met with respect and given time; including relatives in planning care, documenting their opinions and offering them education; acknowledging children, mapping their social network and offering age adapted information and support; and offering support to parents with mental illness in their role as parents (Stenström 2009). These principles, which take into consideration the needs of families living with mental illness, go well in line with other studies that illuminate the importance of involving the family in care plans and offering them information, support and education (i.e. Rolland 1999; Farvis 2002; Leggatt 2002; Gavois et al. 2006).

The Internet as a Health Care Tool
Strengths
The last ten years’ rapid advances in Internet technology have turned the Internet into an interesting and attractive space for health related information and services. A multitude of different players are active in the creation of e-health sites today and offer patients, as well as health care personnel an extensive amount of information about diseases, services and networks. Knowledge and information are useful coping tools and the Internet offers an important platform to spread information. The Internet as a health care tool has advantages and disadvantages that are important to take into consideration. The Internet can be a cost-effective tool to spread information by reaching out to a wide public at low costs. It is convenient and can be accessed 24/7 wherever there is access to a computer and an Internet connection. Physical distance and time do not matter on the Internet in the same way as they do in real life communication. On the Internet, people can easily communicate over geographical distances and also without the other person being online at the same time. The Internet’s synchronous and
asynchronous communication channels make it possible to correspond with people in different time zones and different countries regardless of the distance and time differences.

The Internet can hence be used as a complement to regular health care services, which in turn may be facilitated through different applications of the technology within the health care system. For instance, informed and empowered patients and their relatives may find that their dialogue with health care professionals may be facilitated thanks to the information found on the Internet; although research suggests that not all physicians welcome such empowered patients (Coulson and Knibb 2007). Furthermore, the Internet can be used to book appointments and may offer possibilities to be in contact with health care professionals, for instance through interactive question and answer sections on websites. Suggestions to use the Internet for preventive purposes, including the provision of information and counselling, have also been made (Ross et al. 2000; Tikkanen 2000). The Internet should not be a replacement for regular care services, but rather a complement. It does not suit everyone to use the Internet for health related matters, but since its worldwide use is presently growing expansively, possibilities to use this technology constructively for health enhancing purposes should be further explored.

Perception of Anonymity
If the design of systems and protocols on the net offer a sense of anonymity and privacy, it may have a disinhibitory effect on information seeking online (Joinson 2003). This may be especially beneficial for stigmatizing conditions (i.e. mental illness, alcoholism), for instance, enabling people to access relevant information anonymously from their homes or from any other chosen location with Internet access. It may also be useful for people that are shy of face-to-face contacts. It seems like the anonymity offered by the Internet can be beneficial for groups of people with marginalized social identities. The Internet can be a source of contacts with people, who share the same kind of marginalized identity (McKenna and Bargh 1998), reducing the feeling of isolation and enhancing the possibility to receive support, eventually leading to the disclosure of this identity in real life thanks to the emotional and motivational support found online.

It is interesting to see how Internet use affects identity and self-presentation. A rather well-known characterization is that the Internet offers opportunities to experiment with different facets of the self and various personas without fear of disapproval from the social circle, thereby facilitating self-expression (Turkle 1995). An alternative perspective is offered by Bargh et al. (2002), who postulate the existence of a “true self”. They claim that the relative anonymity and other
properties of the digital media imply that expression of the “true self” is more predominant in Internet communication than in face-to-face meetings. Persons showing their true self will be more likely to form close and meaningful Internet relationships (McKenna et al. 2002). Anonymity also permits role playing on the Internet. An individual can easily take on different personalities and try out different roles; roles, which may be sanctioned or difficult to take on in real life due to criticism, strong reactions or stereotyping by friends and family, who do not expect such changes (Bargh et al. 2002). The enhanced capability to adopt different roles may lead to a changed self-concept and increased feelings of self-worth and acceptance (McKenna and Bargh 1998).

Weaknesses
Among the Internet’s disadvantages, quality and confidentiality issues can be named. Anyone can set up a website with information of varying quality, and in worst cases with misleading and dangerous information. Studies have shown that the quality of information on depression on health related websites is generally poor (Griffiths and Christensen 2000). National and international organizations cooperate on developing strategies to help Internet users find and assess websites with reliable and qualitative information, for instance through filtering techniques or quality markers on the website (i.e. the Health on the Net Foundation’s HONlogo)(Health on the Net Foundation, Jul. 2008). Furthermore, Internet users can misuse identities and cues to body language are limited. The lack of identifiability may lay the ground for deceptive behavior and conscious misrepresentations of the self in order to deceive others. Feldman (2000) observed four cases of misuse of virtual support groups, where individuals offered false stories of personal illness or crisis in order to get attention, sympathy, to act out anger or in order to control others. There is also a risk of “negative and antisocial behavior on computer networks” (Joinson 2003, p.64), so called flaming. It includes antagonistic and aggressive behavior against other users of chat rooms, for instance. It seems like flaming and more uninhibited verbal behavior are more common in anonymous real-time discussions (such as computer-conferencing, chat room discussions) than in face-to-face communication (Siegel et al. 1986). Online support group users risk being exposed to abuse and personal attacks due to the disinhibitory effect on the net (Finn and Banach 2000); however flaming in online support contexts appears to be scarce (Joinson 2003).

As seen, the Internet has advantages and disadvantages for the delivery of health information and services online. An introduction into the e-health concept will now follow.
E-health
Actors and Driving Forces
The international organizations World Health Organization (WHO), European Commission (EC), International Telecommunication Union (ITU) and European Space Agency (ESA) have officially adopted the denomination “e-health” (Jordanova 2005). It refers to “the use of modern information and communication technologies to meet the needs of citizens, patients, healthcare professionals, health care providers, as well as policy makers” (EU Ministerial Declaration, 2003, in Jordanova 2005). More narrowly, e-health can refer to the Internet delivery of health care services, including direct care such as counseling or psychotherapy (Maheu and Gordon 2000). Utbult (2000) defines e-health (“näthälsa”) as following: ”the Internet as a source of information and meeting place for the exchange of knowledge and experiences, for patients and health care personnel” (my translation). Utbult (2000) divides e-health into three different categories: the communities’ e-health, the public health care’s e-health and the commercial portals’ e-health, mainly financed through advertising.

Many different actors are present on the e-health market, including a variety of associations and societies, institutions, governmental and non-governmental organizations and foundations, Telecom and IT (Internet) companies, and military structures, to name a few (Jordanova 2005). The following main driving forces are thought to be behind the e-health market (Jordanova 2005): competition with the health care industry, newly developed cheap IT solutions and the 21st century’s health care consumers with their expectations of free choice and a high level of health care (Mittman and Cain 2001). The four major identified segments - citizens, patients, professionals and employees – can have needs, expectations and boundaries that may overlap (Jordanova 2005). Diverse e-health activities can be identified, including health related commercial activities, such as the provision of clinical services and equipment, health insurances and medicines; and e-health websites, which can be either interactive, such as support groups, or non-interactive, such as plain informational websites (Jordanova 2005).

Prerequisites and Hindrances to the Expansion of E-health
E-health presupposes e-literacy; that is the ability to surf the web, but also to critically evaluate the reliability, accuracy and source of online information and services (Androuchko 2005). It also requires cooperation between telecommunication operators and health care professionals, and proper training of health care professionals in using e-health services (Androuchko 2005). A proper telecommunication infrastructure, and preferably interoperability among
systems, is also a necessary prerequisite for the usage and spreading of health related services over the Internet (Androuchko 2005). The National Board of Health and Welfare in Sweden works on several levels to incorporate a national IT strategy, including the legislative level, the information and technical structure, purposeful IT systems and accessibility of information over organizational borders and to the people. In order for health care related information to be purposeful, the needs and requirements on information of involved parties need to be taken into consideration (Socialdepartementet et al. 2007).

According to Utbult (2000), there are three factors that might slow down or hinder the development of e-health: the digital divide, the insecure economic calculus and the credibility issue. The digital divide refers to the fact that not everyone has access to computers and to the Internet, among others due to socioeconomic reasons. Gaps can be: technical, with gaps in infrastructure; a content divide, with lots of web based information not being relevant to the real needs of people; a gender divide, with women enjoying less access to information technology than men; a commercial divide, with e-commerce creating bonds between certain countries and companies while marginalizing others (Annan 2003). But also social, economic and other obstacles can affect the ability for all to enjoy digital opportunities equally (Annan 2003), for instance experience, age, motivation and degree of education (Utbult 2000). The insecure economic calculus alludes to difficulties in assessing the economic advantages and difficulties related to health websites (Utbult 2000). Varying quality and reliability of information online make the credibility factor an important one for the Internet’s further development and use as a health care tool. Initiatives aiming at controlling and assessing the quality and reliability of health information online have been taken by a number of national and international organizations.

Legislative, Ethical and Quality Guidelines
The use of the Internet to deliver health services raises a number of important questions concerning the service users’ safety, privacy and confidentiality. Practitioners’ qualifications, fees and types of interventions are also subject to questioning (Maheu 1997; Barak 1999). Empirical research is needed to verify the efficacy and appropriateness of different types of online interventions and services. Several initiatives to develop ethical guidelines for websites have been observed in the last decade. The Internet Healthcare Coalition (IHC) introduced its eHealth Code of Ethics in 2000 (Adams 2000). The American Medical Association, the Health on the Net Foundation (HON) and the Health Internet Ethics (Hi-Ethics) are other examples of groups behind such initiatives (Adams
Their approach consists of building trust and protecting privacy rather than focusing on increased governmental regulation (Adams 2000). The different initiatives may have slightly different codes, but have agreed on working towards creating a set of standards and a common glossary. Examples of keywords are trust, confidentiality, protection of privacy, safety, transparency, updated and professionally reviewed information. IHC, for instance, focuses on certifying employees and educating them in handling ethical problems more than on accrediting websites (Adams 2000). Several actors on the e-health arena seem to agree on the fact that the industry should work on regulating itself, paying close attention to ethical issues, before governmental initiatives impose ever more restricting regulations on health related websites (Adams 2000). Initiatives that aim at helping users assess websites’ quality provide three different kinds of tools (Kiley 2000): badges of approval to websites fulfilling defined quality criteria; rating tools for users to assess the quality of any website; web technology in form of filters for medical information. The Health on the Net Foundation (HON) for instance recommends a code of conduct based on eight principles when designing health websites; a website fulfilling these principles can apply for a badge of approval.

It is of interest to explore how the Internet can be used in the support to relatives living with mental illness, especially since it is an under-prioritized group within the health care system. Social support has shown to be an important mediating factor in relation to health (i.e. Skärsäter 2002). Social support can be found within social networks, which can be created and maintained online as well as offline. A few words about social support in relation to depression will follow, succeeded by a section on social networks and the access to social support off- and online.

**Networks and Social Support**

Social support has been defined and measured in different ways in the scientific literature, showing on a complex and multidimensional concept. A metasynthesis of findings from qualitative studies and linguistic analyses led to the following definition: “an advocative personal process that is centered on the reciprocal exchange of information and is context specific” (Finfgeld-Connett 2005, p.5). Whether emotional or instrumental, support is preceded by a need for social support, a social network and a climate conductive to the process, with improved mental health as outcome (Finfgeld-Connett 2005). A widely accepted definition of social support includes the following dimensions: emotional, instrumental, informational and appraisal assistance (House et al. 1985). Different perspectives
can be taken into the definition of social support, namely the type of social support, recipients’ perception of received support, support providers’ intentions or behaviors, reciprocity and social networks (Hupcey 1998). The definition in use naturally affects which variables are being measured, how they are perceived and can affect health outcomes.

**Depression and Social Support**

Previous research has demonstrated that social support is a buffering and mediating factor influencing physical and mental health (i.e. Skärsäter 2002; Takizawa et al. 2006). Nevertheless, more research is needed to identify which supporting processes stimulate the transition from depression to health in depressed persons (Skärsäter 2002). Takizawa et al. (2006) found that social support had a buffering effect on depression under stressful circumstances in middle aged males that were both providing and receiving support, but not in women. Social networks, not to be mixed up with social support, can be sources of both stress and social support (Wellman 1981; Gottlieb 1983; Berkman 1985). Social networks can have negative effects on health when they are experienced as more demanding than helpful and cause stress (Coyne and DeLongis 1986). The stressful interaction model and the negative provider support model sustain the idea of negative support, while other social support models including one or multiple providers sustain the idea of helpful support (Hupcey 1998).

Skärsäter (2002) found differences in men’s and women’s patterns in coping with major depression with the help of professional and lay support. However, both professional and lay support were needed to help men restore a place in the public domain, and both men’s and women’s coping styles entailed social support. This illuminates the importance of support from family and friends to cope and recover from depression, and of assisting both patients and families in empowering their social networks so as to access viable sources of support.

Among patients with treatment-refractory depression, every other patient, mostly women, experienced insufficient social support and principally lacked emotional support (Skärsäter et al. 2001). In patients experiencing sufficient support, the best support was felt to come from outside the family (Skärsäter et al. 1999; Skärsäter et al. 2001). Research has shown that people primarily seek social support in their closest networks, including family and friends, and more rarely turn to health care personnel for that purpose (Hupcey and Morse 1997; Hupcey 1998; Finfgeld-Connett 2005). Emotional support from close relatives or friends has shown to affect women’s mental health positively and to be a predictor of good mental health in men, but not in women (Fuhrer et al. 1999).
Patients with major depression were more exposed to stressful life events, including increased arguments with family members and partners, as compared to healthy volunteers (Skärsäter et al. 2001), reflecting a strained situation for family members too. Not only the patient, but also his/her closest network experiences stress and an increased burden, which can give rise to needs of support and information (Stjernswärd and Östman 2008). Relatives may hence be a source of social support to depressed patients and contribute to a faster remission and prevent relapse, as much as negative family interactions may worsen symptoms of depression, slow down remission and induce relapse (Vaughn and Leff 1976; Hooley et al. 1986). Nevertheless, it shows the importance of attending to family members’ needs to help them cope and prevent ill health, but also to help relatives support the depressed patient.

Health professionals, communicating with patients and their families, are in a key position to promote patients’ social networks, which may be potential sources of social support (Hutchison 1999; Finfgeld-Connett 2005) and to create links to professionals (Hutchison 1999). Skärsäter et al. (2001) illuminate two essential nursing tasks, namely supporting the patients and their network, as well as educating them about the effects of depression on daily life and others (Cohen and Syme 1985). Temporary sources of social support may compensate for a potential lack of social support and health workers may for instance recommend participation in a support group to enhance social support (Moos 1990).

Several studies have shown an association between low support and psychiatric symptoms with the most common psychiatric disorder being depression, however with an unknown direction of causality (Orth-Gomér 1987). Causality is difficult to establish since depression affects both the availability of support and the perception of its adequacy (Orth-Gomér 1987). Underlying psychological traits have shown to be correlated with social support measures, with socially isolated persons being rated as more depressed (Orth-Gomér 1987). Social support may have a buffering effect against stress and a lack thereof, social isolation, may represent a stressor in itself, thereby influencing health and disease processes in different directions depending on its availability and adequacy (Orth-Gomér 1987). Clinical depression can be predicted by the lack of social support, and depressive tendencies may reduce an otherwise mentally healthy person’s potential for social support (Orth-Gomér 1987).

Social support can thus play an important role for patients and their relatives in a daily life with depression. As seen, self-help groups can be a valuable source of social support, among others when support is limited. Self-help groups can be found both offline and online; a subject about which more will follow next.
Social Support Offline and Online

Self-Help Groups Offline

Karlsson (2006) defines self-help groups as a “small gathering of individuals that regularly meet to handle a common problem through mutual help and support” (p.5, my translation). A number of characteristics have been put forward that typify self-help groups (Karlsson 2006). They are limited in size, meet regularly, and participants share a common problem that is addressed through mutual support. Sharing a common problem leads to a mutual understanding and the insight that other persons share the same problem, making it possible to exchange practical experiences. The group is balanced in the sense that all participants are equally important and have experiences to share with the others, all being both help givers and receivers (Karlsson 2006). Self-help groups generally rest on a principle of anonymity and don’t require registration or only registration under an anonymous identity (Karlsson 2006). Nowadays, meeting similar others sharing common problems has been simplified through the Internet, where support groups can be found only a few clicks away.

Karlsson (2006) puts forward different explanations to the expansion of self-help groups. They may be the result of our society’s increased focus on individual choices, with the individual as producer and not only as consumer. Another explanation is the harsher economical climate, where self-help groups can be viewed as cost effective treatment alternatives. A further reason may be skepticism towards the caring professions, partly related to individuals experiencing a lack of or incorrect care and wanting to be more active in defining their own life situation instead of leaving it in the hands of the caring professions. Self-help groups can also be the result of a will to understand one’s situation, for which access to others’ experiences and narratives can be useful. People’s need to be understood by others with similar experiences may also motivate participation in self-help groups.

The presence of confounding factors makes it difficult to measure the effects of self-help groups. Asking participants how they experience their participation and its meaning to them is a possible approach. Shared understanding and support, social fellowship, exchange of knowledge and experiences appear to be the most meaningful aspects for participation (Karlsson 2006). Self-help groups have been described as a refuge where people can be together without needing to explain themselves, since most have a shared understanding of each other’s situation (Karlsson 2006). The access to knowledge based on experience seems to be one of the central motivators for participation in such groups (Karlsson 2006). More research is needed to get a better insight into the workings of self-help groups.
and how participants benefit from them, including web based groups (Karlsson 2006). Now more will follow on online networks and the exchange of social support online.

**Online Networks and Social Support**

Within the e-health field, a virtual community is typically defined as “a group of individuals with similar or common health related interests and predominantly non-professional backgrounds (patients, healthy consumers, or informal caregivers) who interact and communicate publicly through a computer communication network such as the Internet, or through any other computer based tool (including non-text based systems such as voice bulletin board systems), allowing social networks to build over a distance” (Eysenbach et al. 2004). Johnson and Ambrose (2006) speak of “neo-tribes”, defined as networks of persons gathering for social interaction. These networks tend towards being loose and ephemeral, gathering and dispersing occasionally, addressing multifaceted health needs that the traditional health care system may or may not fulfill in the offline world (Johnson and Ambrose 2006). Online communities may be complementary arenas for the fulfillment of certain needs, but in no way exclusive in relation to the offline world.

Support groups can define themselves as self-help groups, whether they are professionally facilitated or not. Self-help implies that people with similar experiences can help each other by coming together (Davison et al. 2000). The main reason for participating in such a group seems to be the experience of physical illness (Lieberman 1993). Social comparison theory (Festinger 1954) predicts that anxiety increases affiliative behavior and that individuals seek a sense of normalcy and accuracy about the world, particularly under uncertain conditions. Previous research on the effectiveness of self-help groups has shown positive results, although the measurement of efficacy can be problematic due to the self selected nature of the samples (Davison et al. 2000).

Networks are the source of different kinds of support, be it informational, social, physical or emotional. Although ties online can be weak and between physically and socially distant persons, who are not bound in densely knit community structures, they seem to be the source of reciprocal supportiveness (Wellman et al. 1996). Patients’ online communities (POC) offer a space for the exchange of medical information, social support and health education (Johnson and Ambrose 2006), both on an individual and societal level (Josefsson 2005). POCs offer the benefits of major coping strategies, such as gathering information, interacting with others in a similar situation and helping others (Josefsson 2005).
Empathy, the ability to identify with someone else, is an important ingredient in virtual communities (Preece 1999). Empathy can be provided within support groups amongst fellow sufferers of the same ailment; however, frequently asked questions (FAQ) areas may provide more factual, but not less important information (Preece 1999).

Online support groups can provide a network of weak ties and hence access to resources that may otherwise be out of reach. Granovetter (1982) suggested that weak ties are useful through the provision of access to people different from oneself and consequently access to different and differentiated resources. Strong ties are more often found between people that are more similar to each other and hence provide access to more similar resources. The character of computer mediated communication (CMC) leads to facilitated access to more people and to new social circles and networks, loosely growing through i.e. forwarding friends’ e-mails to other people, entailing access to more diverse ties and better online advice (Constant et al. 1996).

However, social networks online do not only affect networks through enhancing the number and diversity of network ties, but also seem to facilitate the maintenance of strong supportive ties with work (i.e. through groupware for cooperative work) and community (i.e. through newsgroups), as well as intermediate-strength ties between people who cannot meet frequently (Wellman et al. 1996). Relationships in such networks are based more on shared interests than on proximity, and although there is no clear boundary between real life and offline contacts, the net entails specific communication and relational structures and norms (Wellman et al. 1996).

As online support is a growing phenomenon, different models from different disciplinary perspectives have been put forward to describe the process of online social support. The social identity and deindividuation (SIDE) model describes psychosocial aspects related to computer based communication (CMC) where contextual features, such as anonymity and isolation, lead to normative behavior (Spears 2002).

**Anonymity, Stigma and Self-Disclosure**

It appears that illnesses with interpersonal consequences, illnesses that are embarrassing, socially stigmatizing or disfiguring lead individuals to seek support from others with similar experiences, with high levels of support observed in groups for these conditions (Davison et al. 2000). A measurement of the support levels in illness support groups for 20 different conditions over a two weeks period showed that the highest levels of activity were observed for multiple
sclerosis and depression in America Online bulletin boards (AOL) and chronic fatigue syndrome, diabetes and breast cancer on Internet newsgroups (Davison et al. 2000). Further, it showed that support seeking, in face-to-face and online support groups, was highest for diseases viewed as stigmatizing (i.e. AIDS and alcoholism) and lowest for less embarrassing but equally distressing disorders (i.e. heart disease) (Davison et al. 2000). Depression was found to be a condition that gave rise to the formation and maintenance of mutual support forums.

Stigma has been identified as a barrier to the treatment of mental illness, including depression (World Health Organization 2001; Sirey 2001). Goffman (1963) identified the phenomenon of “courtesy stigma”, meaning that the effects of stigma are not only noticeable on the person directly marked by the difference or illness, but also on those closely associated to that person. A majority of relatives of persons with mental illness seem to experience psychological factors of stigma by association, particularly relatives with mental health problems of their own (Östman and Kjellin 2002). The families’ potential experience of stigma might restrict their willingness to seek help and support (Wasow 1995).

The Internet has shown to be an interesting medium in addressing stigma through the creation of depression websites. As previously mentioned, the Internet’s perceived anonymity has shown to be potentially beneficial for persons suffering from stigmatized conditions. Powell, McCarthy and Eysenbach (2003) concluded that Internet communities can be used to mediate information and support to persons diagnosed with conditions that hamper more traditional ways of seeking information. With the help of a randomized controlled trial (RCT), Griffiths et al. (2004) showed that websites online contribute to significantly reduce self stigma (reflecting the individual’s personal attitudes) even though the effects were small. BluePages, a depression website, did not affect perceived stigma (reflecting the individual’s belief of others’ attitudes), while MoodGYM, a website with cognitive behavioral therapy online, showed an increase in perceived stigma (Griffiths et al. 2004). It demonstrates that the Internet is a viable medium to address stigma, although its full potential needs to be further explored.

As seen, meeting similar others may positively contribute to self-disclosure and an enhanced acceptance and reinforcement of one’s identity in the offline world (McKenna and Bargh 1998). However, it can be detrimental if the identity entails negative and destructive elements, such as hatred against minorities, which are legitimized through participation in a group supporting these views (McKenna and Bargh 2000). Online groups supporting self-injury and suicide ideation may for instance be examples of detrimental Internet uses, which can affect people negatively and reinforce destructive behavior.
It seems that the sense of not being alone in a certain situation is beneficial to group members (Cummings et al. 2002). Upward social comparison may provide a guide for action (Festinger 1954; Wood 1989), while downward social comparison, making clear that there are people worse off than oneself, may lead to an increase in mood and self-esteem (Gibbons 1986). It also seems that the disclosing of emotional feelings and trauma can be beneficial for the discloser’s well-being in the form of immune system benefits (Pennebaker et al. 1988) and improved affective states (Smyth 1998), which brings us to the subject of expressive writing.

**Writing as Therapy**

*Journal Therapy*

Journal therapy was developed in America in the 1960s and has been defined as the “purposeful and intentional use of reflective or process writing to facilitate psychological, emotional or physical healing and to further therapeutic goals” (Adams 1990). Different journal techniques can be more or less structured (Thompson, in Bolton et al. 2004). Journal therapy may be useful for introverted persons for whom talking about sensitive matters to someone face-to-face may be more difficult and for persons lacking support networks and intimate relationships (Thompson, in Bolton et al. 2004). The journal may represent an alternative venue to express and explore thoughts and feelings.

**Expressive Writing**

The cathartic effects of writing have been illuminated in different disciplines, such as literature, psychology and the social sciences. Research on the potential beneficial effects of expressive writing has been undertaken and shows that this hypothesis is supported, although the mechanisms behind the beneficial health effects are not known (Pennebaker 2000). Different hypotheses have been drawn upon to explain the mechanisms behind therapeutic writing: inhibition, cognitive organization and a theory of social integration (Pennebaker 2000). The inhibition hypothesis refers to the negative health effects of not confiding a traumatic experience, which may be due to social pressure to maintain secrecy, entailing energy craving inhibitory work. This pressure may be released through writing. The cognitive processing hypothesis refers to putting emotional experiences into words and reorganizing and understanding these experiences, which may have beneficial health effects. Not confiding important emotions may lead to a sense of social isolation due to the inability to be honest and open with others. Through writing, emotional experiences are put into words, the experience organized and
better understood, releasing the pressure of inhibition and the sense of social isolation. This may lead to cognitive coherence and closure, and hence healthy benefits (Pennebaker 2000).

Wright and Chung’s (2001) review shows that there is a growing body of literature related to therapeutic writing, both from the humanities’ perspective and a scientific perspective. Wright and Chung (2001) situate this range of literature on a mystery (humanities) - mastery (scientific) continuum, entailing two different paradigms and methodologies. While the humanities talk about the soothing and healing powers of writing, the scientific paradigm, including disciplines such as immunology, health and social psychology, tries to explain, analyze, predict and measure the results of randomized controlled trials (RCT). Experiments and empirical data support the mental and physical health benefits of writing therapy (i.e. Smyth 1998; Pennebaker 2000). Different methodologies have been used, such as RCTs and self-report within case-studies, as well as different outcome measures, such as psychological measures (cognitive, affective and behavioral effects), physiological measures (i.e. immune function), and general health measures (i.e. somatic complaints, health care visits) (Wright and Chung 2001). For the purpose of their review, Wright and Chung (2001) define writing therapy as “client expressive and reflective writing, whether self-generated or suggested by a therapist/researcher”.

Within the humanities’ paradigm, theoretical ideas from different disciplines are represented, such as psychoanalytic theory, linguistics, symbolic interactionism and philosophy (Wright and Chung 2001). Within this paradigm, creativity is seen as the most important ingredient of writing therapy (Wright and Chung 2001). Creative and autobiographical writing are linked to personal development and healing (Hunt and Sampson 1998), self-help, prevention and self-directedness, as well as physical and psychological benefits when conducted in small groups (Bolton 1999). Representatives within this paradigm support the idea of confronting previously undisclosed emotions and private insights in writing, in combination with potential support and challenge in facilitated groups, and recommend experiential methods for users and practitioners/researchers, since the mechanism behind the positive effects are difficult to explain.

Within the scientific paradigm, researchers try to capture the positive effects of expressive writing through experiments. Pennebaker’s (Smyth 1998; Pennebaker and Seagal 1999; Pennebaker 2000) positive results have been replicated with different populations and across different countries. Smyth (1998) also found beneficial physiological effects, with a positive impact on the immune system. Nevertheless, the physical and psychological health benefits are still difficult to
explain. References to learning theory and the processing of traumatic events, and to self-confrontation and cognitive reappraisal can be found in this paradigm (Schoutrop et al. 2002).

L’Abate (2000) illuminates the potential of computer-mediated therapeutic writing, an intervention that can be done at a distance, but under professional supervision. Workbooks with home assignments can be developed and based on different theoretical or empirical perspectives. The use of writing for therapeutic purposes in the context of cognitive therapy has a long history and computer-mediated methods can replace pen and paper (Wright and Chung 2001). The delivery of computer based cognitive therapy is a growing area that is subject to research. Studies have shown that such computerized delivery can have positive effects on depression symptoms (Christensen and Griffiths 2002; Andersson et al. 2005; Andersson 2008), but further RCTs are wished for to support and strengthen these results. The advantages of computer-mediated workbooks include cost effectiveness, replicability of intervention method and the possibility to evaluate therapy in writing more easily than verbal therapy (L’Abate 2000).

The advantages of writing in a therapeutic process have been related to the client’s possibility to control the rate, depth and intensity of therapeutic work, as well as to the fact that it can be private until the client decides to share what he/she has written (Rasmussen and Tomm 1992).

Studies of the use of computer mediated therapeutic writing are needed. However, writing therapy may not be appropriate or beneficial for all people and/or conditions (Wright and Chung 2001). Previous research identifies a number of contraindications, such as psychoses (Bolton 1999), dyslexia and the association of writing with negative criticism (Lange 1996). Initially, writing can lead to negative mood and short-term psychological pain (Esterling et al. 1999), which on a longer term basis make room for positive psychological well-being (Pennebaker 2000).

Depression and Expressive Writing

Expressive writing – writing about important personal experiences in an emotional way – may contribute to lower depression symptoms in depressive prone individuals, especially for people that have a tendency to ruminate and draw on suppression and avoidance of negative thoughts (Gortner et al. 2006). Expressive writing may lower tendencies to ruminate (constant attention to symptoms, their causes and consequences); a behavior that may increase chances of depressive episodes. Furthermore, it may promote cognitive processing of adverse events, preventing depressive episodes. Those that benefited the most
from expressive writing used a high number of positive-emotion words and a moderate number of negative-emotion words, with an increased use of cognitive words over time. This may reflect a process in which writing helps organize and understand complex emotional experiences, leading to enhanced physical and mental health (Pennebaker and Seagal 1999). This allows processing the event and leaving it behind. However, booster writing sessions – additional sessions besides the regular writing sessions - did not enhance treatment benefits (Gortner et al. 2006). These findings have been replicated across different populations in different countries; however further research is needed to confirm these results and to understand if and how expressive writing promotes health (Meads and Nouwen 2005). One possible explanation is that the creation of a narrative may help individuals integrate thoughts and feelings, their emotional reactions to the traumatic event, while organizing and thinking about the trauma in the form of a story composed of words (Pennebaker and Seagal 1999). A number of participants in an expressive writing study actually started writing a diary after the experiment because of its perceived beneficial health effects (Gortner et al. 2006). Since families living with mental illness are at risk of their own mental health problems (Östman and Hansson 1999/11), expressive writing may be a useful self-help tool.

Empowerment and Coping

Empowerment

Empowerment has been described as a process whereby “people gain mastery over their lives” (Rappaport 1987). It aims at enhancing “the patients’ self-understanding and the potential of self-care” resting on the following foundations: awareness, freedom, choice and responsibility (Feste and Anderson 1995). Hope is a central concept and people are encouraged to identify their values, needs, goals and resources (Feste and Anderson 1995).

Feste and Anderson (1995) describe three methods of empowering patients living with a chronic disease: the use of questions to stimulate the exploration of how the disease affects daily life and how it can be integrated into different levels of one’s life (i.e. personal, social, professional) and questions related to personal philosophy and personal dreams. Secondly, they suggest the use of behavioral language, including words such as describe, identify, define, decide and list, which encourage action taking and decision making. Thirdly, the authors suggest storytelling as an empowering technique, since it encourages self-discovery. Discovering that one can become the author of one’s own life story can also have an empowering effect (Feste and Anderson 1995).
Therapeutic writing and written communication with others online may thus be useful tools to promote empowerment. These techniques may also be useful to enhance coping strategies.

Coping
According to the scientific literature, coping can be viewed from a trait/style perspective or as a process. From the trait perspective, coping is inherent to the individual and stable and consistent over time and conditions. From the process view, coping is defined as “constantly changing cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person” (Lazarus and Folkman 1984). When demands are greater than resources, a stressful balance can occur.

Coping as process has two major functions (Folkman and Lazarus 1980). The problem focused function aims at obtaining information about what to do to handle a situation and act on it. Problem focused strategies (PFC) are used in situations appraised as amenable to change and when stressful situations are appraised as challenges, leading to growth. Emotion focused coping aims at regulating the emotions tied to a stressful situation. Emotion focused strategies (EFC) are used in situations estimated to be chronic and when stressful situations are appraised as threats. They are possibly associated to depression and low self-esteem (Lazarus and Folkman 1984; Dysvik et al. 2005). Problem solving skills and social factors affecting self-esteem can be enhanced through group approaches thanks to positive feedback and acceptance (Mruk 2006).

Communicating online with similar others that offer comfort and support may hence enhance self acceptance. Self-help groups, offline and online, may thus be interesting arenas for the exchange of support and information, which are well known coping strategies (Lazarus and Folkman 1984)).
METHODOLOGICAL CONSIDERATIONS

Qualitative explorative methods were used in the present studies, including grounded theory and content analysis. A paradigm is a set of beliefs that define the researcher’s worldview and their ultimate truthfulness can never be established (Denzin and Lincoln 1998). Paradigms encompass three elements: epistemology, inquiring into how we know the world and the relationship between the inquirer and the known; ontology, inquiring into the nature of reality; and methodology, focusing on how we gain knowledge about the world (Denzin and Lincoln 1998). Grounded theory, which is the predominant research methodology of the work presented here, is usually described as endorsing a realist ontology and a postpositivist epistemology, but with some differences depending on the version of grounded theory, with later versions endorsing constructivist ideas (Charmaz 2000). Constructivist approaches to grounded theory acknowledge the position of mutuality between researcher and participant and the presence of the author’s voice in the final product (Charmaz 1996).

Grounded theory – Epistemology and Ontology
Postpositivism
As mentioned, grounded theory has been situated in the postpositivist paradigm (Kennedy and Lingard 2006), being a reaction to some of the positivist ideas, but still with positivist underpinnings. Annells (1996; 1997) characterizes Glaser’s version as endorsing a “critical realist” and a “modified objectivist” perspective.

Denzin and Lincoln (1998) describe postpositivism in the following way. The ontology endorsed by postpositivists is critical realism, entailing that reality is assumed to exist, but is only imperfectly and probabilistically apprehendable due to human intellectual flaws and the intractable nature of phenomena. The epistemological stance is a modified dualist/objectivist one. Dualism, implying that the investigator and the investigated are assumed to be independent
entities, without reciprocal influence on each other in the study process, is not maintained by postpositivists. However, objectivity is a "regulatory ideal". Replicable findings are probably true, but always subject to falsification. The chosen methodology is modified experimental/manipulative with an increased use of qualitative methods, including the introduction of inquiries in natural settings, the collection of situational information, and discovery as an element in inquiry. Meanings and purposes that people ascribe their actions are solicited, contributing to "grounded theory".

These stances are critical reactions towards the positivist tradition, where the endorsed ontology is realism, the epistemology is dualist/objective, and the methodology is experimental and manipulative. Gaining knowledge in a postpositivist tradition hence entails looking for a reality that exists, but that can only be partially rendered or found, and which can also be modified or falsified by new data. The researcher tries to be objective, however he/she is aware of the fact that both the investigator and the investigated can have an influence on each other; an influence that the researcher tries to minimize through different techniques depending on the choice of method.

Two Versions of Grounded Theory

**Symbolic Interactionism**

Symbolic interactionism has its roots in Mead’s (1934) and Blumer’s (1969) work. In short, symbolic interactionism is based on the following principles: people act toward things based on the meaning those things have for them; these meanings are derived from social interaction with other people and society; and these meanings are modified through interpretation (Blumer 1969). It is a social constructionist approach to understanding how people create meaning during social interaction, how people present and construct their self or identity, and how they define their social roles (Fine 1993). Symbolic interactionism is based on the idea that people act as they do in function of how they define situations. The self is thus given meaning through the individual’s choices, which are mediated by the person’s relationships, situations and cultures (Fine 1993).

**Glaser – Strauss and Corbin**

Grounded theory is a research method that has been subject to debate, partly due to the split between its two co-originators Glaser and Strauss. Grounded theory emerged in the 1960s when Glaser and Strauss cooperated on a sociological research project on dying in hospitals. Together they wrote *Discovery of grounded theory: Strategies for qualitative research* (Glaser and Strauss 1967).
Grounded theory was a way of challenging the logico-deductive trend. It provided an alternative to the verificational tradition prevalent within sociology at the time (Glaser and Strauss 1967). The idea was to combine the strengths of both quantitative and qualitative approaches, combining the depth and richness of qualitative interpretive traditions with the logic, rigor and systematic analysis found in quantitative research (Glaser and Strauss 1967; Charmaz 2000). Instead of developing a theory to be tested and verified, grounded theory entails collecting data and systematically deriving theory from empirical data. Grounded theory can be used both on quantitative and qualitative data, although the latter is more common. In grounded theory all is data, meaning that all kinds of data can be used, for instance transcribed interviews and diary notes. The method originated in the social sciences, with a presently growing number of studies using grounded theory within sociology, psychology, nursing and education (Jeon 2004). The method entails both inductive and deductive elements and is often described as an inductive method with deductive elements.

Glaser and Strauss developed grounded theory in different directions; however, the basic research process in both versions is the same, entailing gathering data, coding, comparing, categorizing, theoretically sampling, the development of a core category and a theory (Walker and Myrick 2006). Glaser’s coding procedure involves two steps: substantive coding, entailing both open and selective coding, with the aim of generating categories and their properties, and theoretical coding, which happens at a conceptual level. Selective coding starts once the core category has been identified and implies coding around a core category. Theoretical coding leads to hypotheses to be integrated into a theory and describes how the substantive codes relate to each other. The coding method proceeds using the constant comparative method. Memos should be written continuously to record emerging conceptual and theoretical ideas.

In grounded theory, the processes of sampling, data collection and analysis are done concurrently and iteratively in the sense that data collected from a sample is analyzed inductively and steers the next coming sample, which then can be said to be deductively based on the analysis. This process goes on until a theory has been generated and saturation has been reached. Saturation means that further data collection does not add anything new to the emerging theory. The analysis process is carried out using the constant comparative method, implying that incidents are compared to incidents and new incidents to existing categories. Through this process, the important elements, and eventually a theory, will emerge from data and hence be grounded in data. The aim of grounded theory is not to test hypotheses but to generate new theory, either substantive theory (setting specific)
or formal theory. Glaser (1992) means that if the constant comparative method is properly and thoroughly used, the comparison itself acts as a verifier of data, grounding the emerging theory in data.

Theoretical Sensitivity, Reflexivity and Literature Reviewing

Grounded theory implies avoiding the use of a predetermined framework in the research process in order to avoid bias and being steered by preconceived notions (Glaser 1998). Data collection should be steered by the emerging ideas and theory as the analysis proceeds, and not by any previously developed theories. Both Glaser and Strauss speak of theoretical sensitivity - being sensitive to emerging concepts and not being desensitized by preconceived concepts - although it is achieved in different ways. While Glaser (1992) means that immersion in data and constant comparison leads to theoretical sensitivity, Strauss and Corbin (1990; 1998) suggest the use of specific tools to reach theoretical sensitivity. Glaser (1992) argues that Strauss’ method forces the data in preconceived ways instead of encouraging emergence.

Charmaz (2000) stresses the importance for researchers of acknowledging the influence of prior work or experience on their perspective. For Glaser (2001), reflexivity means being self aware and is important; nevertheless, it should not stifle creativity by forcing researchers to locate their work within a particular theoretical context. Strauss and Corbin (1990) advocate for reading the literature early with the following arguments: it stimulates theoretical sensitivity and questions, it provides a secondary source of data and supplementary validity, and it directs theoretical sampling. Glaser (1992), however, argues for reading the professional literature related to the study area after the analysis has been completed, so as not to bias the results or start working with a framework of preconceived ideas. Codes and categories should emerge from data.

Content Analysis

Originally, in the 1950ies, content analysis dealt with quantitative descriptions of the manifest content of communication. But currently qualitative content analysis is also common, for instance in nursing research (Graneheim and Lundman 2004). Qualitative content analysis can be used on different kinds of data and be carried out on different levels of interpretation. Interpretations can vary in depth and in level of abstraction, with the analysis being either manifest, with focus on the visible contents, or latent, referring to the underlying content (Graneheim and Lundman 2004).
Graneheim and Lundman (2004) describe the analysis process with a number of steps, starting with a definition of the unit of analysis. Thereafter meaning units - groups of words or statements that relate to the same central meaning - need to be identified. The next step entails a condensation of the text, which must be shortened without losing the core. Thereafter follows abstraction, including descriptions and interpretations on a higher logical level, which can be done using codes, categories and themes on different levels. Codes are the meaning units’ labels. Categories describe the manifest contents and regroup similar contents. They can include sub-categories at different levels of interpretation. Themes and sub-themes deal with the latent content, entailing a deeper interpretative level.

The method’s roots in quantitative research traditions entails that quantitative concepts (i.e. validity, reliability, and generalizability) still prevail when speaking of trustworthiness. However, qualitative content analysis can make use of concepts stemming from qualitative research traditions to measure and achieve trustworthiness; concepts like credibility, dependability and transferability. Credibility refers to the confidence in how well data was collected and analyzed to address the intended focus (Polit and Hungler 1999). Dependability taps into the extent to which data changes over time and to which the researcher’s decisions alter during the analysis process (Graneheim and Lundman 2004). Transferability refers to the extent to which the findings can be transferred to other settings or groups (Polit and Hungler 1999).

The digitally based tool was developed using an iterative design process, of which the principles will be described below.

**Iterative Design Process**

In the present project, an iterative process was used, including user centered design, to develop prototypes and the digitally based tool. The following section describes best practice in the development of IT systems, including attention to usability. Consideration to usability requirements facilitates the development of prototypes, which are then tested with users in empirical studies, and prevents that users get stuck in their use of IT systems due to usability problems. For interactive products to be easy, effective and enjoyable to use from users’ perspective (Preece et al. 2002), user centered design methods are valuable. Consideration needs to be taken to user characteristics and contexts of use, as well as to the kind of activities that the users will carry out when interacting with the product.

Iterative refers to the design process involving cycling through design processes at different levels of detail (Preece et al. 2002). It entails thinking through a design problem, understanding users’ needs and requirements, developing
conceptual models and eventually prototypes through user centered methods. The prototypes shall then be tested and evaluated with respect to usability and user experience goals, and further developed according to the feedback gathered from evaluations. The design process hence moves forward through iterations that reach increased depth as the process goes along.

Within user centered design, users are actively involved in development and cooperate with the designers in designing the product (Preece et al. 2002). It is a good approach when willing users are available to become actively involved in the design process. Participation in this process can increase users’ sense of ownership of the product and for the designers, it entails a beneficial contact with users (Preece et al. 2002). However, users’ thinking can be constrained by what they know, and too much user involvement can lead to boredom and counter-productive input (Preece et al. 2002).

Usability, “the extent to which a specific user can use a specific product to reach specific goals, with purposefulness, effectiveness and satisfaction, in a given context” (ISO 1998) is important for users’ acceptance of a system (Allwood 1998). Preece et al. (2002) set a number of goals in the design process to maximize usability, namely effectiveness, efficiency, safety, utility, learnability and memorability (Preece et al. 2002). Effectiveness means that the system does what it is supposed to do, while efficiency refers to the way the system supports the users in carrying out tasks. Utility is defined as the extent to which the system provides an appropriate set of functions that enable users to do what they need or want to do. Learnability refers to how easy the system is to learn and memorability to how easy it is to use the system and remember how to do it once learned. Further tools can be used as a help in the design process, such as development and ethical guidelines, and heuristics for evaluation.

Formative evaluation aims at refining and formulating the design process through feedback about users’ opinion of the design (Faulkner 2000). Formative evaluation focuses on qualitative data. Summative evaluation usually focuses on quantitative data and aims at “assessing the impact, usability and effectiveness of the system – the overall performance of user and system” (Hewitt 1986). It gives a measurement of the system’s performance improvements. Formative and summative evaluation can be used complementary and at different stages of the design process.
AIMS

The overarching aim of the present research project is to explore the possibility of using the Internet to support the relatives in their daily life when living close to a person with depression. More specifically, the aim is to:

• Get an overview and comprehension of the e-health landscape, with special focus on depression.
• Explore what the Internet offers the relatives of persons with depression as of this day.
• Further explore a group of relatives’ experiences of living close to a person with depression.
• Explore the possibility of developing a digitally based tool through an iterative design process in close cooperation with potential users.
• Explore users’ experiences of the digitally based tool.
METHODS

Design
The present project was carried out using a qualitative explorative design. It started with a short survey of the e-health landscape with focus on depression, including searches on databases, search engines, reference lists and through Pew Internet and American Life Project’s website. Thereafter, a closer look was taken at a number of websites found through the Health on the Net Foundation’s search engine MedHunt to see what they offer relatives living close to a person with depression. The next step entailed an exploration of relatives’ experiences of living close to a person with depression using individual interviews and focus groups. Next, a digitally based tool aimed at supporting the relatives in their daily life with depression was developed through an iterative design process in cooperation with potential users of the tool. This was followed by an exploration of users’ experiences of the tool and its usability. A description of the methodological decisions will follow below.
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**Samples**

**Study I**

Searches were performed on a number of databases (Medscape, PubMed) and search engines (http://www.yahoo.com, http://www.alltheweb.com) with the terms “Internet + depression” on Medscape (October 29, 2004), and “Internet health depression” and “Internet and depression” on PubMed (October 29, 2004). The searches resulted in 53, 150 and 138 hits respectively. Three additional items were found through Pew Internet and American Life Project’s website. All relevant articles were screened to get an insight into the field. However, the present illustration of the subject area is based on peer reviewed articles of ongoing trends in the field.

**Study II**

The websites explored in the course of the second study were retrieved through a search process using the Health on the Net Foundation’s (HON) search engine MedHunt. This was chosen due to concerns regarding the quality of the studied websites. Searching websites through another commonly used search engine, such as http://www.yahoo.com, could have been an alternative sampling method. However, there was a strategic interest in choosing HON’s search engine. HON is an international organization working with qualitative aspects of health related information online. Using MedHunt hence gave an insight into the strengths and weaknesses with HON’s ambitions to help health seekers locate qualitative health information. The search process eventually resulted in 22 websites that were analyzed in the course of the second study.

**Studies III, IV and V**

Participants in the third, fourth and fifth studies were recruited through a number of different channels. Participants were recruited through a psychiatric ward, a support organization, advertisement in regional newspapers and through a national online support group. Inclusion criteria were age (18-65, papers III-IV) (18-70, paper V) and being a relative/significant other of a person with depression. These channels were chosen with concerns for heterogeneity. Most participants were recruited through the support organization and the paper advertisements.

**Participants**

Eighteen persons between the ages of 35 and 65 partook in the third study (paper III). Prior to the interviews, a pilot interview was carried out to test the topic guide with open ended questions. Eleven women participated in individual interviews.
Eight women and three men partook in four different focus groups of 2 to 4 persons each (2, 2, 3, 4). Participants were partners (6 women, 2 men), mothers or fathers (6), daughters (3) or best friend (1) of a person with depression. Most participants were born in Sweden (14) and two thirds shared household with the ill person (12). Most participants (16) had a partner. Approximately half of the participants had children under 18 in the household (7). The majority lived in a city or smaller community (16), while two lived in the countryside. The majority had a higher education after high school (14). All but one worked. Eleven participants had used the Internet to look for information on depression and five had searched for support groups or material online, but few found the information or material useful.

Of the eighteen participants in the third study (paper III), eight partook in one of two separate focus groups in the fourth study (paper IV). Participants in the first focus group consisted of three women and one man, aged 44-65 and were partners (3) and a mother (1) of a person with depression. Their Internet experience was varied, with one person hardly having any Internet experience at all. Participants in the second focus group consisted of four women, aged 42-58, also with differing levels - from little to fairly good - of Internet experience. Their relationship to the ill person was partner (2), an ex-partner and mother (1), and a mother (1). Most participants had partners (7) and shared household with the ill person (7). Six participants lived in a city or small community, while two lived in the countryside. All worked and five had a higher education. Half of the participants had used the Internet to look for information on depression, but only two had looked for support groups. Most did not find the information useful though.

In total, twenty participants registered onto the website to participate in the fifth study (paper V), but four persons dropped out early on for different reasons (too little time and/or energy to participate in the research project, the ill partner disliked the relative’s participation in the research project). Sixteen persons thus completed the full test period (10 weeks). A number of participants had previously partaken in the project and some were freshly recruited through advertisements in two regional newspapers in Southern Sweden. All participants, but one, were women between 35-68 years. They were partners (8), parents (5) or grown-up children (3) of a person with depression. The majority of participants had partners, lived in a city or small community, worked, had a higher education and were born in Sweden. Approximately half of the participants lived full time or part time with the ill person, while the others did not. Two thirds of the participants had searched for information about depression online and only three for support online. A handful found the information partly useful.
Registration Procedure (Paper IV)
All participants that had signed an informed consent were sent an e-mail (December 8th, 2008) with a link to the registration area of the website. Details asked for on the registration page were the participants’ name, address, e-mail, phone number, as well as a user identity and password. It also included a control question with answer to help users retrieve their password in case of loss. Only the users knew their password. Participants also had to cross a box showing that they had read, understood and accepted the rules and recommendations for the website (rules and conditions, disclaimer, integrity and security policy), which could be opened and read in pop-up windows. Once the registration procedure was fulfilled, an e-mail with a link confirming the registration was sent to the registered participants and had to be clicked on by the participants to validate the registration. On January 7th (2009), all registered participants were given full access to the website, entailing a forum and a diary, as well as information about the research project, about the website and its services, instructions for the diary and forum, news, and online formularies for contact with the responsible for research and the web expert.

Data Collection
Interviews and Focus Groups
The data for several studies in the present thesis was collected through individual interviews (paper III) and focus groups (papers III, IV and V). The interviews in the third study (paper III) were carried out in a location chosen by the participants (home/office/Malmö University). All focus groups (4 groups of 2, 2, 3 and 4 persons respectively) were carried out at Malmö University. The interviews lasted between 62-105 minutes (paper III) and were carried out by the first author. An assistant moderator also participated in the focus groups, taking notes.

The two focus groups (4 persons in each group) in the fourth study (paper IV) lasted 60 and 80 minutes respectively and were carried out by a moderator (first author) and an assistant moderator. Paper based and web based prototypes were used to illustrate the tool to be. Notes were taken on a board and collected for analysis.

The three focus groups in the fifth study (paper V) consisted of 5, 4 and 4 persons respectively and lasted between 60 and 75 minutes. To minimize bias, the focus groups were carried out by an external interviewer (second author, paper V) and using an interview guide. In individual interviews, as much as in focus groups, the interviewer’s or moderator’s ability is crucial to the outcome. The moderator’s role is to ask questions and to control group dynamics (Morgan
It is important for the moderator to develop a topic guide encouraging discussion (Barbour 2005).

**System Usability Scale**

Fourteen out of 16 participants (paper V) answered a Swedish version (Piatidis 2002) of the system usability scale (SUS) (Brooke 1996). All participants answered the scales prior to the interviews. However, one participant that could not partake in a focus group sent the filled scale by regular mail. Two out of 16 participants fulfilling the complete test period could not partake in focus groups and did not fill the scale due to practical or health reasons. The present mean is thus based on 14 answered questionnaires.

SUS is generally used after participants have tested a system, but before follow-up discussions. It entails 10 questions about a system’s usability. A space for additional comments was added in the present version. Possible values on every question are 0-4 and the total value 0-100. The latter represents the subjective total assessment of the evaluated system’s usability. A SUS value over 70 can be estimated as good, and over 85 as excellent (Bangor et al. 2008). Summary statistics for SUS scores for a total of 2324 surveys show that the mean score is 70.91 with a median of 75 and a 0 to 100 range (Bangor et al. 2008).

**Forum Posts and Statistics**

All the writings in the forum stemming from the 10 weeks test period (January-March 2009) were printed out and analyzed with permission from their authors, including from those that dropped out prior to the end of the test period. Statistics from the website’s administrative section showed that the visible activity grade (submitting and answering forum posts) within the forum varied amongst participants (1-11 postings per user). Nevertheless, the reading and/or lurking frequency could not be extracted from the website statistics. In total, there were 57 posts on 10 different subjects, with a reply mean of 5 postings per post, and a mean reply frequency of 2 postings per person. The most active participant posted 11 postings while the least active only posted one, which several participants did. Two of the posts were initiated by the moderator (first author) to spur discussions at the start and middle of the test period. The first question was: 1. What is the most difficult to handle as a relative of a person with depression? The second post specifically enquired into users’ experiences of using the forum and was: 2. How do you experience participating in the forum? What thoughts and feelings does it awaken?
The frequency of diary entries among all participants varied between 1 and 31 over the 10 weeks test period, with a total of 105 entries by the end of the period. Half of the participants made between 7-31 entries, while the other half made between 1-3 entries during the test period.

Data Analysis

Study I
A quick and dirty survey of the e-health landscape in relation to depression was carried out with the aim of getting an insight into the named field. The articles were screened for initiatives and research in the field of e-health and depression. For quality assurance motives, the relevant peer reviewed articles were chosen to illustrate the field and a descriptive account was made based on their contents. Focus was not so much on the quality of the articles as such as on their contents since the aim was to get an overview of the field, and not to make a review for evidence based and effect-assessment motives.

Studies II and III: Grounded Theory
Qualitative data was analyzed using a grounded theory inspired methodology (papers II, III) (Glaser and Strauss 1967). Since little was known on the subject, this method seemed appropriate to explore the substantive areas of interest, entailing web based material for the families of persons with depression and the relatives’ experiences of living close to a person with depression. All kinds of data can be used with grounded theory (Glaser 1998). The analysis proceeded using the constant comparative method as suggested by Glaser and Strauss (1978). It proceeded through different stages including substantive coding, entailing open and selective coding, and theoretical coding. The samples were limited to the websites retrieved by the Health on the Net Foundation’s search engine Medhunt (paper II) and to the number of participants willing to partake in the study (paper III), making the theoretical sampling limited. Nevertheless, saturation appeared to be reached as no new information changing the emerging theory did come out. This does not hinder that further data may contribute with new information, since it is always difficult to assure that saturation has been reached although it may seem so.

Studies IV and V: Content Analysis
Qualitative data (papers IV, V) was analyzed using content analysis (Graneheim and Lundman 2004). Collected data consisted of focus group discussions (audio-taped and transcribed), participants’ (paper IV) and the moderator’s (papers IV-V)
notes from the focus groups and forum writings. These were the units of analysis, which were read repeated times to get a sense of the whole. In the course of the analysis, meaning units relevant to the research questions at stake were extracted, condensed and abstracted into categories and sub-categories. Thereafter, the emerging categories were screened against the original units of analysis to make sure that they covered all essential data. Although categories should aim at being exhaustive and mutually exclusive, the latter can sometimes be difficult when dealing with human experiences (Graneheim and Lundman 2004). The emerging categories and final results were discussed amongst the authors to strengthen the findings’ trustworthiness.

Study V: System Usability Scale (SUS) and Statistical Data
Quantitative data was described with the help of mean values and range, which were both calculated for the system usability scale (SUS). Website statistics from the site’s administrative section showing participants’ use of the website were collected and reported as such, describing frequency of use of the diary and forum. Lurking was however not discernible in the statistics.

Ethical Considerations
Studies I-V
The project as a whole was approved by the Regional Ethical Committee in Lund, Sweden (275/2006, 414/2008). An additional ethical approval was requested and received for the last two studies once the idea for the digitally based tool had crystallized over the project’s course. Participation was voluntary and could be interrupted at any time without any further explanation from the participants. All participants signed an informed consent prior to their participation.

The administrators of two web based forums were contacted for approval to recruit participants through their respective forums; so was the support organization’s committee before the researcher presented the project for the recruitment of participants during one of their regular meetings. Permission to recruit participants through psychiatric wards in the south of Sweden was also given by the Head of the Psychiatric Department.

Collected data was handled so as to protect participants’ integrity and identity. Confidentiality was ensured. All participants in the fifth study (paper V) gave their consent to use the writings in the forum as research material. They were clearly informed, orally and in written, prior to their participation in the study. Information about this was also displayed on the website developed in the course of the fourth study (paper IV).
Participation in focus groups can compromise anonymity, however participation was voluntary and participants were informed about the study’s set up prior to participation.

Internet based tools always imply a certain security risk, such as i.e. hacking. Measures were taken to maximize protection of participants’ integrity, security and identity, such as i.e. a password protected website membership, encryption of the diary, incentives to use an alias and not display personal information that may reveal users’, their relatives’ or third parties’ identities in the forum. Not only partakers but also their ill relatives must be protected so as not to get in trouble by participating in the research project. Considerable work, reflection and discussions were carried out regarding security and integrity issues related to the development of the website and its evaluation within the research team, including the web expert.
RESULTS

Paper I
The first study gives an overview of the e-health field in relation to depression. It shows what kinds of research and initiatives online have been carried out with focus on depression. Diverse initiators with differing goals and motives are active in the e-health field and display different initiatives online. Research from a number of different areas was found, such as studies on the use of online support groups and cognitive behavioral therapy (CBT) online. A reduction of depressive symptoms has been observed with CBT online, although further research is needed to prove the effectiveness of Internet delivered intervention programs.

Research relevant to the field also contributes to describe user profiles of health seekers and online community members, and reliability and qualitative issues related to health information online. Fox and Rainie (2002) found that the typical health seeker is generally female and middle aged, between the ages of 30 and 65. Further, highly educated and Internet experienced individuals are more frequent health seekers than individuals with lower education and/or Internet experience. People reporting fair or poor health are more likely to search health information online than those reporting excellent or good health. Furthermore, broadband access supports seeking health information online. Fox and Rainie (2002) noted that the main reasons for going online for health information are worries about someone's health, being diagnosed with a medical condition and prescribed a new medication, and being a caregiver to someone else.

Fox and Fallows (2003) found that out of 80% of the American adult population seeking for health information online, 17% of men and 25% of women searched information about “depression, anxiety, stress, or mental health issues”. The quality of web based information about depression can be varying, although several sources describe it as being generally poor. Nettleton et al. (2005) observed that health seekers show a certain awareness about the
trustworthiness of health information online. Nevertheless, research shows that the majority of health seekers do not use systematic quality assessment strategies when going online.

Research of online communities shows a high frequency of users with depressive problems, representing a target for intervention. Fox and Fallows (2003) found that participation in health related support groups online is increasing. Research shows that it can improve feelings of well-being. Nevertheless, privacy concerns and the wish for face-to-face contacts can be hindrances to joining such groups. Misuse of support groups has also been observed.

**Paper II**
The second study shows what type of material is available for the relatives of persons with depression on a number of websites (22) retrieved through the Health on the Net Foundation’s search engine MedHunt. Analysis of data shows that there is little material for families, especially comprehensive material on one single site. The core category consists of the “absence or presence of supportive or other material for the relatives or significant others of depressed persons”. The main categories are “no specific information”, “basic facts”, “for significant others to help the depressed person”, “for significant others to help themselves”, “in the margins of society: on legal issues and stigma”, “among equals: online communities and support groups”, and “sharing of personal experience”. The material thus addresses problems related to depression from different perspectives.

The study also gave rise to a model, or so called basic social process (BSP), illustrating different kinds of material from the websites in relation to the parties concerned by the illness, namely the ill person, the relatives and society. While the focus of some material is on depressive symptoms, for instance, and thus on the ill person, other material addresses the relatives’ feelings or encounters with the health care system in form of information on coercive treatment, for instance.

The study shows the existence of a variety of material from diverse originators. Nevertheless, it points to a lack of relevant and comprehensive material specifically aimed at families living with depression. More can be done to reach out to a target group in need of support.

**Paper III**
The study illuminates the relatives’ experiences of living close to a person with depression. The majority of participants experienced a growing and sometimes overpowering feeling of not living their own life (core category). This was the basic social psychological process identified amongst the participants in the
third study. This feeling arose from processes related to difficulties balancing relationships, a process of adaptation and re-evaluation of life circumstances, and a struggle to act advocate and voice for the person with depression within the health care system and society.

Naturally, the process can be affected by the severity and duration of the illness; however, all participants were more or less affected in their private, professional and/or social life. Constantly worrying about the ill person, additional household duties and other responsibilities, such as contacts with the health care system added to the daily burden. The dynamics of the relationship were easily transformed or reinforced to that of a nurse/patient or parent/child character, where the patient/child needs much care and attention. This took energy from other relationships, whether it was to other family members, friends or professional tasks.

Living close to a person with depression also gave rise to strong emotions that are not easy to handle single handedly, such as feelings of guilt, anger and shame. Other frequently awoken feelings were frustration, sorrow, regret and worry. Hopelessness, powerlessness and resignation were not uncommon in relation to the health care situation when relatives did not feel that they were being heard, seen or taken seriously. The study shows that the relatives live in the shadow of depression and that their needs are rarely addressed and/or met within the psychiatric services. More can thus be done to reach out to and support families living with mental illness.

Paper IV

In this paper, the design of a digitally based tool for the relatives of persons with depression was described, and motivations and obstacles to using online self-help tools were explored. It illuminates users’ thoughts about private versus public aspects of such tools, highlighting the importance of privacy issues, and guiding design decisions. Based on a theoretical framework including expressive writing and online social support, it was decided that the tool would entail an online diary and forum.

Motivations to use the diary are to rehabilitate oneself, with the subcategories: to ventilate thoughts and feelings, to create a breathing space and find one’s own voice, to give hope and strength; and to create understanding, with the subcategories: for one’s own feelings, for the patient, to see patterns and draw conclusions, and as a basis for health care visits. Hindrances are the lack of time and energy, the lack of access to or experience of computers, the risk of exposure, difficulties expressing oneself in writing and a wish not to think about the situation during good periods.
Motivations to use the forum are the contact with similar others, with the subcategories: to find a feeling of community and enlarge the social network, to decrease feelings of loneliness and social isolation, and to compare experiences; reciprocal exchange, with the subcategories: to support and encourage each other, to exchange advice, and to create meaningfulness by helping others; to create insight and understanding, with the subcategories: understanding of one’s own feelings, understanding of the patient, see patterns and draw conclusions, and decrease stigma; and anonymity, with the subcategory openness and honesty. Hindrances are the lack of time, the risk of exposure, and false identities and stories.

Prototypes were used in the focus group discussions to illustrate the concepts for the tool and involve users at an early stage to guide the design process. Privacy concerns guided a number of design decisions, such as making the diary private and encrypted and the forum accessible to members only. To allow for more privacy within the forum, an e-mail function was included so members can have contact with individuals of choice. The diary entails scales to measure variables of interest for the relatives to monitor over time. Participants clearly wished for the variables’ focus to be on them and not on the ill person, since the tool is aimed at supporting the relatives. This guided the choice of variables: it was decided that they would monitor negative (i.e. sorrow, frustration) and positive (i.e. personal growth) feelings related to the depression, and to which extent the illness affects the relatives’ daily activities and leisure time.

**Paper V**
The fifth study illuminates users’ experiences of the tool developed in the course of the fourth study. The website entails an online diary, private and encrypted, including scales, and a forum, members only access, including an e-mail function. The theoretical framework behind the tool is based on the potential health benefits of expressive writing and the buffering effects of social support in relation to depression. Based on the different data, the results illustrate the functions of the diary and forum for its users. Through analysis of the forum writings, it appears that the diary works as a place of discharge and a think tank, and the lack of routines can be a hinder to use it regularly. The forum works as a place of discharge, contributes to a sense of community and the exchange of experiences, support and information. Privacy concerns were thus mentioned.

The analysis based on the focus group discussions shows that the website works as a communication instrument, with the self and others. It also shows advantages and obstacles related to the Internet as a technology for the present tool, and
feedback on the website’s use and contents. The website allows communication with the self, with the sub-themes: think tank and perspective, duty and reminder versus enjoyment, and place of discharge and privacy. The website also allows communication with others, with the subthemes: sense of community, exchange and perspective, critical mass and activity level, empowerment and openness, and anonymity.

Amongst the technological advantages, it can be named that ease and convenience of use from different locations were appreciated. Further, qualities such as independence of time and place, constant availability and discretion were valued. The lack of familiarity with online forums and computers can thus be an obstacle, which can be overcome with help from the moderator and web expert.

The system usability scale (SUS) shows a mean of 78, showing good usability, and a range of 43-98. The website’s name, www.sommarregn.se, meaning summer rain, was appreciated, especially since it does not directly relate to depression, but still can refer to the relatives’ state of mind at times. The diary and forum were seen as separate things, although their presence on the same site helps give nourishment to the writings in the different areas (diary and forum respectively). The instructions and diary scales were only partly used by some participants, if at all, while others did use them more thoroughly. The e-mail function was appreciated although not used much. A number of participants missed to use a pseudonym within the forum due to a lack of familiarity with a forum’s workings, which led to worries about privacy. Although the use of a pseudonym was strongly recommended in the instructions and user rules, some participants missed to use it, showing that this point may need more highlighting in a future version of the website. The participants appreciated the contacts with the researcher and the web expert, representing an opportunity to ask questions and working as an incentive and reminder to use the tool.

This study also illuminates the relatives’ wishes in relation to specific information and services online. For instance, they wished for tips on books, articles and cultural events related to depression and advice from professionals, pointing to areas for further development.
DISCUSSION

Methods
The overall design of the present project was qualitative and explorative, including an iterative design process. It proceeded through a number of steps, including a short survey of the e-health field with focus on depression, a closer look at material online for the relatives of persons with depression, the exploration of relatives’ experiences of living close to a person with depression and next, the development through an iterative design approach of a digitally based tool aimed at alleviating relatives’ hardships in a daily life with depression. The last step was an exploration of users’ experiences of the tool and the latter’s usability. This approach was useful to reach a better understanding of the relatives’ experiences and needs, and an essential step in the tool’s development. At this stage, professionals were not included in the design process, but their participation is important in the further development of the tool. The health care system’s acceptance of and active participation in the construction of digitally based tools are essential for a successful implementation of functional systems.

Justifying Knowledge and Methods
Grounded theory seems to be an increasingly used method within the medical sciences and has been used to do research on stories of illness, for instance to understand people’s experiences of living with a certain illness. As seen, different versions of grounded theory are available. It is important that researchers clearly describe which method they have chosen and, if they choose not to slavishly stick to one version, to explain the deviations from the chosen version. Transparency and clarity may help readers evaluate the quality of the study and situate it in a paradigm with accompanying beliefs. The choice fell on the original version of grounded theory, namely Glaser’s, which is based on the principle of emergence. Glaser criticizes Strauss’ version for forcing preconceived ideas on data (Glaser
Nevertheless, curiosity about Charmaz’s (2000) version, which entails more constructivist ideas, was awoken through this project. However, grounded theory has its origins in symbolic interactionism, which includes the idea that people’s identities are shaped in interaction with others and society, a process through which, in combination with interpretation, things acquire meaning. These ideas show that individuals create their understanding and conception of the world in interaction with others.

Once an epistemological position is chosen, an appropriate methodology and method should be chosen that match the epistemological stance for internal consistency in the research process. Grounded theory is a possible choice of method, although it influences the outcome. The interest in the present study was more in grounding the results in a group of relatives and potential users of the tool than in developing a theory as such. The process could have been inverted, starting with the development of a tool, followed by testing and evaluation by users after an assessment by health care professionals. The latter is a stage that can be addressed in future developments of the tool. Starting with users had the advantages of grounding the knowledge in the target group and assessing the acceptance and usefulness of the tool within this group prior to its further development.

According to Glaser (1998), the criteria legitimizing a grounded theory are the following: the theory should fit the substantive area; it must work to explain relevant behavior in the substantive area of research; it must be relevant to the participants; and it must be readily modifiable as new data emerges. Further data collection within grounded theory is done to enrich a theory and not as a means of verifying previous data. New data may prove parts of a theory wrong, but a theory will never be entirely wrong since it is grounded in data; however it is modifiable. If all the steps of grounded theory are properly and thoroughly applied, including the constant comparative analysis, theoretical sampling and theoretical sensitivity, the findings verify themselves by being grounded in data, requiring no further validation (Glaser 1998). Our second and third studies resulted in basic social (psychological) processes grounded in data and explaining the main problem in the studied areas.

Epistemology influences the relationship between the researcher and the participant, in the sense that it shapes the researcher's conceptualization of the participant in data collection and analysis (Carter and Little 2007). Either the participant will be seen as an active contributor or as a subject being studied. Grounded theory has its roots in symbolic interactionism, thereby acknowledging a mutual influence between the researcher and participants. Epistemology
influences form, voice and representation in the method, with a more or less present researcher’s voice and role in the research report (Carter and Little 2007). Through questioning and reflection, the researcher’s preunderstanding can be made visible. The researcher hence acknowledges his/her presence and stance in the research process in an attempt at being as objective and unbiased as possible. Previous knowledge needs to be addressed and handled appropriately so as not to let it steer the research process. These steps were followed in the present project and memos were written continuously during the research process.

The research process should be free from preconceived concepts within the “Glaserian” tradition of grounded theory (Glaser 1998), which advocates for accessing the second body of literature after completion of the analysis. Within grounded theory, all is data (Glaser 1998), allowing the researcher to interview him-/herself and to incorporate the data into the analysis as further data. The researcher hence tries to maintain an “objective” and neutral voice in the research report, among others by acknowledging previous knowledge and perhaps using it as further “objectified” data in the analysis process.

Objectives, research questions and design shape the choice of methodology and vice versa (Carter and Little 2007). Practical limitations may influence the choice of methodology. Different analysis methods will produce different accounts of the same data. While an analysis based on grounded theory may result in a theory, a narrative analysis will result in a detailed analysis of life stories (Carter and Little 2007). Another method could have been used in the present papers (papers II-III); however, due to the limited amount of research in the studied areas and the researcher’s previous experience with grounded theory, the choice fell on the latter.

Content analysis was used in the two last studies (papers IV-V). An epistemological assumption in Graneheim and Lundman’s (2004) paper on content analysis is that reality can be interpreted in diverse ways and that understanding results from cooperation between the researcher and the participants, thus being dependent on subjective interpretation. Again, this points to the interaction between the researcher and the participants and to the importance of reflexivity, entailing an active process of self-questioning and reflection.

**User Centered Design**

The ambition with the present project was to develop a digitally based tool using an iterative design process and prototypes. Cooperation with users was one step in addressing and pursuing the state of the art standards in system development, such as those described by ISO 9241-11 (ISO 1998). ISO 9241-11 describes how to define, document and verify the quality of a product. Besides planning the
human centered process, user centered design requires designers to specify the context of use, user and organizational requirements, to produce design solutions and to evaluate designs against user requirements. Consideration was taken to these steps throughout the design process. The system usability scale eventually showed good usability (mean of 78) (paper V). The results based on focus groups and forum writings also show interesting results with the tool filling valuable functions to its users (paper V).

A continual dialogue took place between the author and web expert to maximize the tool’s usability and incorporate ethical standards at an early development stage. This close cooperation was valuable in continually illuminating technical possibilities and limitations in developing this type of digitally based instrument. A number of tools were used to guide the design process, such as heuristics for expert evaluation with guidelines for the site’s navigation, access and information (Preece et al. 2002), a framework to guide the evaluation of interactive products (DECIDE) (Preece et al. 2002), the Health on the Net Foundation’s Code of Conduct (HONCode) (Health on the Net Foundation Jul. 2008), the European Commission’s recommendations (Europeiska Gemenskapernas Kommission Jul. 2008), advice from an expert in law and information technology (to secure the veracity of information displayed on the website, to moderate the forum, to take action in case of illegal activities within the forum, and to display a disclaimer) (Westman Dec. 2008) and the U.S. Department of Health and Human Services’ (HHS) Research-Based Web Design and Usability Guidelines (U.S. Health and Human Services Department 2006). Focus was also on maximizing usability to ensure that the tool is easy to learn, effective to use and enjoyable from a user perspective (Preece et al. 2002). The results from the fourth and fifth studies (papers IV-V) speak for good usability, but areas for modifications and enhancements were also illuminated.

The process could have included further iterations, possibly enhancing the tool’s usability and further development. However, the present iterations fulfilled the needs at this stage. Further iterations can be included in the subsequent development and assessment of the tool. The website was evaluated using mainly qualitative data reflecting users’ opinions of the tool, equaling formative evaluation (Faulkner 2000) with data collection occurring through focus groups. Participants’ writings in the forum were also subject to analysis with the aim of exploring the tool’s meaning for its users. A usability scale was used to assess participants’ subjective experience of the website’s usability. Descriptive statistics on the website’s administrative pages were also used. These methods were found to be suitable to explore users’ experiences of the tool and to make sure that
major usability issues did not prevent users from testing the tool. User centered
design as an approach in the present project was not a research method per se,
but was aimed at facilitating the development of a testable tool and prototypes.

Trustworthiness

Sampling

The sampling in the first study (paper I) could have been described in more detail,
included additional databases and search terms for a more thorough first survey.
A proper systematic review may have been called for. Nevertheless, the study’s
aim was not be all encompassing or to assess the articles’ or the initiatives’ quality
as such, but rather to get an overview of and orientation within the e-health field
with focus on depression.

The second study’s sample (paper II) was limited to the number of websites
retrieved through MedHunt, which was chosen as a sampling method out
of quality concerns. The principle of theoretical sampling could thus only be
followed to a certain point. However, saturation was felt to have been reached.
If new data arises through additional studies, it can be used to modify and/or
enrich the emerging theory (Glaser 1992). Naturally, other sampling methods
(i.e. searches on the most popular databases) and content analysis could have
been used as alternatives. The scarcity of research in the subject area combined
with a wish for deeper knowledge of grounded theory contributed to the choice
of method. The fact that all can be data and the constant comparative analysis
method were appealing aspects of grounded theory. So was the idea that the main
issue or problem in the studied area and the way it is being handled emerge as the
data collection and analysis processes continue. Besides the possible shortcomings
in the sampling stage, the constant comparative analysis and the principle of
theoretical sensitivity were applied throughout the research process. By following
these steps, the findings are grounded in data and verify themselves (Glaser 1992).

The samples’ limited size (papers III, IV, V) may limit generalizability of
the results. However, the studies were explorative and did not primarily aim
at generalizability, but at illuminating a special area of interest. Further studies
with larger and more varied samples, and possibly differing targets, may help
assess the findings’ generalizability. A longer test period in the fifth study (paper
V) may have permitted participants to get used to the system and participate
more actively over time. The fluctuating character of depression is also a factor
influencing the use and function of the website. Participation during more or
less difficult depressive periods can influence how and how much the system
is used, as seen in the fifth study (V), in which participants mentioned a more
frequent need and use of the system during tougher periods. This may affect the results. However, the representation was varied in the present sample (paper V). Some of the participants’ ill kin were suffering from a depression during the test period, while others were in remission at the time. The findings may therefore be representative of a sample participating in a longitudinal study. In future studies, the tool’s use and value can be tested for the different phases of depression (i.e. onset, depressive episode, remission and relapse).

Data Collection and Analysis

Qualitative interviews aim at obtaining descriptions of the interviewee’s world with the purpose of interpreting a phenomenon’s meaning (Kvale 1997). Data generated through focus groups is of qualitative nature and does not aim at numerical generalizability, but rather at depth and conceptual qualitative data (Ivanoff 2002), transferability and theoretical generalizability (Barbour 2005). The group dynamics and interaction involved in focus group interviews enhances data collection (McLafferty 2004).

Krueger (1998) recommends that focus groups should be conducted by two persons, with one person focusing on moderating the group, while the other persons takes notes and handles practical issues (i.e. recorder, etc.). Furthermore, the moderator must try to handle group dynamics to try to avoid that one person dominates the group and that others do not speak up (Patton 2002). McLafferty (2004) suggests that groups with participants unknown to each other may require more moderator involvement as compared to groups with participants that know each other.

The focus groups in the third and fourth studies (papers III, IV) were carried out by a moderator (first author), with the presence of an assistant moderator. In the fifth study (paper V), an interviewer (second author, paper V) that had not partaken as actively as the first author in the development of the digitally based tool carried out the interviews. The choice of a different interviewer in this study was motivated by the wish to minimize bias and enhance the results’ credibility. The interviewer’s extensive experience of interviewing and a momentary lack of resources led to the decision not to have an assistant moderator in the fifth study (paper V). Nevertheless, the data collected through these focus groups was as rich as the data from previous focus groups (papers III-IV) and no significant problems were encountered during the transcription.

Patton (2002) mentions that participants may enjoy focus groups as a social gathering. A disadvantage lays in the fact that a person realizing that his/her views may be a minority opinion may choose to withhold those (Patton 2002).
Therefore it can be a good point for the moderator to prepare the participants to the fact that different opinions may arise during the discussion and that all opinions are welcome in order to enhance the moderator’s understanding of the studied phenomenon. This was done in the present studies (papers III, IV, V). Throughout the interviews, the interviewer probed the interviewees for additional and deeper comments and checked that the answers were understood correctly. The discussions were summarized at the end of every session and participants were given a chance to add further comments and modify possibly misunderstood answers. Participants recognized their answers in the summaries, supporting the findings’ credibility. After the focus groups, debriefing, including a discussion of first impressions took place between the researchers (papers III, IV, V).

Morgan (1996) suggest four to six focus groups for saturation, however if the diversity in group participants or topics is great, more groups can be needed to attain saturation. The number of focus groups in the present studies was limited to the number of willing participants; however saturation was felt to be reached. Focus groups are cost effective means of collecting data in system development using an iterative design process (papers IV-V) (Preece et al. 2002). It is also useful to actively involve users in the design process, identify user requirements and for evaluation purposes (Löwgren 1993; Preece et al. 2002).

Triangulation of methods, entailing combinations of individual interviews and focus groups (paper III), of focus groups, forum writings and statistics, as well as a system usability scale (paper V), was used to strengthen the findings’ credibility. Through a combination of methods (paper III) including individual interviews and focus groups, the advantages of both could be merged. Focus groups can help get an insight into the reality of the interviewees as seen through their own eyes. This, and the possible involvement of participants in the development of health related programs, enhances the chance to satisfy the target group’s needs (Ivanoff 2002). The productivity of individual interviews seems to be superior to that of focus groups in terms of number and quality of generated ideas (Morgan 1996). However, focus groups can be useful in the sense that participants can explain themselves to each other and agreements and disagreements within the group can expose the level of consensus and diversity of opinions, as well as group behaviors and motivating factors behind changes of heart (Morgan 1996). Both the diversity of opinions and social processes can be explored (Kitzinger 1994). The data from both the interviews and focus groups was rich and similar in contents.
A weakness of focus groups is the requirement of mutual disclosure (Morgan 1996). Some topics may not be suited for focus groups; however, the AIDS Media Research Project showed that this method could be well suited for sensitive and embarrassing topics (Kitzinger 1994). This was shown in the present study too (paper III). Medical sociologists have used focus groups with people who share stigmatized or “taboo” conditions (i.e. mental illness) (Kitzinger 1994). Furthermore, this method was useful in identifying group norms and social processes in the articulation of knowledge, through the identification of censured information (Kitzinger 1994). Morgan (1996) acknowledges the benefit of focus groups for interviews on sensitive topics.

Categories and themes (papers I-V) emerging through data analysis were discussed within the research team (researcher, supervisors and assistant moderator) until consensus was reached, strengthening credibility. Consensus was reached between the researchers to ensure that the categories or themes cover the data well, without excluding relevant data or including irrelevant data (Graneheim and Lundman 2004). The participation of partakers with various experiences (i.e. various relationships to the ill kin, differing ages) strengthens credibility. Nevertheless, additional data collected through further studies with more varied and larger samples may contribute to modify and enrich the findings, although saturation was felt to be reached.

A measure to maximize dependability was the use of interview guides and consistency in the questions asked to the participants. The issue of dependability was also addressed through discussions of the results amongst the researchers. Whether the present findings are transferable to other populations and settings or not is up to the reader to evaluate, based on the description of the research process, including the context, selection and characteristics of participants, data collection and analysis (Graneheim and Lundman 2004). A thorough description of the research process was aimed at to help the readers assess the findings’ transferability. Further studies may help shed light on this factor.

**Results**

The present thesis illuminates a number of needs in the relatives or significant others living close to a person with depression. Living with mental illness can affect daily life in many ways, including the private, social and professional areas. This can result in a growing feeling of not living one’s own life, with families living in the shadow of depression. Personal relationships and daily activities are put under hard pressure, leaving diminished energy and attention to social life and professional duties. This corroborates previous research showing that
families living with mental illness can experience an added burden (i.e. Fadden and Kuipers 1987; Badger 1996b; Östman et al. 2005). Although the present thesis also shows that the experience of living with mental illness can entail a positively appraised knowledge and personal development, it is accompanied by strong emotions, hardships and possibly health problems that are rarely attended to by health care professionals. As shown by Rolland (1999), an illness’ onset can be both an opportunity for growth and deterioration of family relationships.

Since resources within psychiatric care are scarce, alternative technologies and support options need to be explored to attend to patients’ and their families’ needs. The Internet is used by a growing share of the worldwide population. With its advantages and drawbacks, it needs to be further explored as a medium to deliver supportive interventions to target groups in need. The fact that a growing number of people turn to the Internet for support and information may be an indicator that this medium is attractive and has gained acceptance by the public.

The first two studies (papers I-II) give an insight into the e-health landscape in relation to depression and into initiatives, or the lack thereof, targeted at families living with the illness. In spite of the many different initiators of e-health projects, the absence of tailor-made and comprehensive services for the relatives living close to depression is manifest. Nevertheless, such initiatives stemming from diverse originators are presently popping up and being developed, such as websites for children and youngsters whose parent is suffering of mental illness (i.e. Kuling Sep. 2009; Organisationen Maskrosbarn Sep. 2009; Forskningsprojektet PS Young Support Sep. 2009).

A Technology for Supportive Communication

Computer mediated communication (CMC) displays a number of technological advantages that can be appealing and useful in the context of mental health interventions. The present project’s findings (papers IV-V) corroborate previous research showing that convenience of use - making it easy to utilize the website both from home and work – and anonymity make the Internet an interesting venue for the delivery of support. Accessibility (ease and speed, convenience), social support, as well as learning and discussing about coping strategies were identified as reasons for participation in an online support group for food allergy (Coulson and Knibb 2007), findings concurrent with the present studies (papers IV-V).

The fact that communication with others is independent of time and place was also appreciated in our study, giving these virtual encounters an advantage over real life meetings, which are less flexible. Since the illness sometimes monopolizes
the energy, this flexibility may be decisive for encountering similar others or not. Online support groups may thus become a lifeline or point of entry to seek help for persons that do not have the time or opportunity to meet similar others in real life. Naturally, virtual meetings shall not replace face-to-face meetings, but can be a good complement.

Previous research shows that anonymity is advantageous in support groups dealing with stigmatized identities or conditions (McKenna and Bargh 1998; Davison et al. 2000). Online interviews for research purposes have for instance shown that anonymity on the Internet facilitates self-expression and removes the hinder of offline shyness (Daneback 2006). Mental illness is still the subject of stigmatization, which can be a fatal barrier to seeking appropriate treatment (World Health Organization 2001; Sirey 2001). Overcoming stigma by creating an allowing climate and opening up a dialogue about mental illness may be valuable steps in addressing this problem.

The findings in the fifth study (paper V) show that participants felt strengthened in their role as relatives without feeling stigmatized, leading to increased openness and empowerment. Communicating with similar others and discovering that they have comparable experiences appear to decrease feelings of loneliness and promote a more open communication with others, including the patient. The forum may thus be a tool in fighting stigma. Anonymity, which was also a prerequisite for the forum’s use, is hence a valuable advantage.

However, the absence of physical cues and concerns about the quality of information in online support groups have been mentioned as disadvantages (Coulson and Knibb 2007). The absence of physical cues online - unless a web camera is used - leaves out clues, which can be helpful to witness in a supportive process. Nevertheless, the same lack can be considered as an advantage since physical appearance and visual clues can be obstacles in social interactions due to stereotyping and social categorization processes (McKenna and Bargh 2000). Issues related to social acceptance can be addressed within online communities by meeting similar others and reading about their experiences. It appears to contribute to reduced feelings of alienation and social isolation (papers IV-V). Discussing how others handle their problems offers a possibility to compare options and coping strategies. It also helps get perspective on the situation and leads to a sense of relativism (paper V).

**Empowering and Disempowering Effects of Online Communities**
The current studies (papers IV-V) illuminate some of the benefits (i.e. social support, sense of community and exchange of experiences), representing
opportunities for empowerment, and disadvantages (reminder of difficult times, qualitative issues) with online support groups, corroborating previous research. The increase of online support groups has given rise to assumptions about their empowering effects in users although evidence of this is not solid (van Uden-Kraan et al. 2008). There is an inconsistency in the definitions of empowerment in previous research on empowerment and support groups (van Uden-Kraan et al. 2008). Empowerment as a concept is multifaceted - it can refer to different aspects such as locus of control, disease knowledge, choices - and multileveled since it can relate to the individual, group or community level (van Uden-Kraan et al. 2008). Furthermore, empowerment can refer to a process that involves taking control of one’s life and managing disease, and to an outcome, referring to a psychological state.

The empowering and disempowering effects of participation in online support groups were identified in a study of eight online support groups for different conditions (breast cancer, fibromyalgia and arthritis) (van Uden-Kraan et al. 2008), and comparable to the findings in the present project (papers IV-V). The empowering processes were: exchanging information, encountering emotional support, finding recognition and understanding, sharing experiences and helping others and amusement (van Uden-Kraan et al. 2008). The disempowering processes were: being unsure about the quality of the information in the forums, being confronted with negative sides of the disease and being confronted with complainers. Being better informed and confident in dealing with the social environment and the physician, increased optimism and control over the future, enhanced self-esteem and social well-being were a few of the observed empowering outcomes. If applicable to patients, these empowering outcomes may be valid for their relatives too, such as those participating in the present project (paper V). A closer look at these aspects is thus needed to confirm these results in the present population.

The present findings (paper V) show that the forum promotes a sense of community, with participants discovering that they are not alone in their situation, decreasing feelings of isolation. This corroborates previous research showing that many participants’ social isolation decreases through online participation, with new acquaintances that sometimes even go offline, and the replacement of friends that disappeared when patients were diagnosed (van Uden-Kraan et al. 2008). Further, many participants appreciated the opportunity to meet similar others and to ventilate feelings with people that understand their experiences, without being afraid of boring or making their offline social circle more worried about their health, also confirming the present findings (paper V).
While most acknowledged that they would have gotten the same information from other sources, they valued the fact that information was retrieved much easier and quicker through online support groups (van Uden-Kraan et al. 2008). The study’s small sample, possibly biased towards frequent users and women, limits the findings’ generalizability, however they corroborate previous research showing that the exchange of information and support, combined with the special characteristics of computer mediated communication (i.e. anonymity and convenience) are attractive means of coping. Since information and sources of support can be difficult to locate (paper III), easy access to advice online may be valuable in a help seeking process.

The fourth and fifth studies (papers IV-V) pointed to a number of benefits and drawbacks with online forums, which should be further explored to measure their potentially favorable and detrimental effects over time. The authors of a systematic review of the effects of online peer to peer interactions concluded that there was no robust evidence as to any harming effects of online communities (Eysenbach et al. 2004). Neither did they find support for these communities’ effects on the outcome measures of depression and social support. However, the authors pointed to difficulties related to measuring the effects of online communities, since these were only parts of more complex interventions. Further research focusing on online communities solely is thus needed to evaluate their effects on their users. Research is needed to assess the structure, format and target of support groups to maximize their possibly beneficial effects and minimize their possibly negative effects.

Nevertheless, a computer-mediated support group intervention for parents of children with cancer showed that mothers’ depression decreased significantly, as well as fathers’ anxiety and stress (Bragadottir 2008). Both parents perceived mutual support to some extent through participation in the computer-mediated support group (CMSG), and used it for reading messages. Insightful disclosure among women in a peer-directed breast cancer group online was associated with improved emotional well-being and reduced negative mood, supporting the hypothesis that the act of making sense of traumatic events can reduce ruminative thoughts associated with illness (Shaw et al. 2006). Participants in the present project also said that writing allowed to ventilate feelings and to let go of ruminative thoughts (paper V). A study of an electronic support group for eating disorders showed that personal disclosure was the most frequently posted message category (31%), followed by provision of information (23%), provision of emotional support (16%), and other (15%) (Winzelberg 1997). Idealizing comments about suicide and destructive posts were thus a problem leading to a
temporary shutdown of an online discussion forum for eating disorders (Johnsen et al. 2002), illuminating dangers with non moderated online communities. The present forum was supervised by a moderator (paper V). Initiatives were taken to spur the discussion, but no threads were estimated as targets for editing or deletion.

The present studies also showed good acceptance and usability of the tool, even among less computer savvy persons. Several sources show that the Internet can be a viable, and sometimes the preferred source of information, communication, peer contact and support (Flatley-Brennan 1998; Turner et al. 2001; Valaitis and Sword 2005), even for computer naive persons after minimal training (Flatley-Brennan 1998). Individuals that found support through a listserv only spent more time reading online when depth of support from a specific person in their life was low and depth of support online was high (Turner et al. 2001). It shows that online support may compensate for poor support offline and fulfill certain needs of support. This was seen in the present study (paper V), where participants feeling lonely and socially isolated found comfort, support and a sense of community through the forum.

**Benefits of Expressive Writing**

Expressive writing has been associated with physical and mental health benefits in different populations (i.e. medical students, men laid off from their jobs, and distressed crime victims) in all social classes and across different countries (Smyth 1998; Pennebaker and Seagal 1999; Pennebaker 2000). The fifth study (paper V) shows that the participants, consisting of a new population in relation to previous research, experienced the website as useful. The diary promotes expressive writing and storytelling, offering an opportunity to ventilate thoughts and feelings in a more (diary) or less (forum) private space. Dealing with these emotions through the creation of narratives appeared beneficial. It allowed distancing oneself from overwhelming feelings and to look at the circumstances with a different view, giving a perspective on the situation. Whether written for the author’s eyes only (diary) or for an imaginary (diary) or real (forum) audience, the act of writing a story and reading others’ stories were appreciated (paper V). It speaks for the beneficial effects of letting emotions out while creating stories, which may actually reduce and/or prevent inhibition and support cognitive restructuring (Pennebaker 2000), helping the relatives to better understand and let go of their traumas.

Diaries used side-by-side in a therapeutic process against depression showed to be useful as a tool for self-reflection and as a support in dealing with psycho-
logical and physical pain, as well as in providing meaning for women’s experiences of depression (Laitinen and Ettorre 2007). The diary and forum created an appreciated opportunity for reflection in the present study, possibly leading to a better understanding of the situation and a possibility to let go of overshadowing thoughts and feelings (papers IV-V). Multimedia storytelling for children and adolescents has shown to be valuable in addressing depression and self-harm, among other health problems, facilitating an empowering therapeutic intervention (Sharry et al. 2004), supporting the value of storytelling in parallel to a therapeutic intervention. Supervision and/or feedback from health care professionals are not included on the present website, although a moderator supervises the forum. Nevertheless, the website’s users may derive benefits from their writing and online interaction, which may possibly facilitate their communication with health care professionals.

The exploration of the website’s meaning for its users (paper V) shows that some of the reasons motivating journal therapy (Thompson, in Bolton et al. 2004) also motivate the use of the web based diary. A journal is sustainable allowing the development of a relationship and intimacy with the self. It provides a space for catharsis. A story can be repeated endlessly without exhausting any listeners. It captures the reality of the moment and makes it harder to stay in denial. The act of writing confirms existence. And it may be a record of healing that is available for reference and consultation. A study of international students’ writing (Lago, in Bolton et al. 2004) showed that writing was therapeutic and useful for ‘working things through’. Sub-themes of the latter were writing as a psychological ‘container’, writing as a personal route to understanding and writing having an interpersonal value. Similar themes appeared in the fifth study (paper V), where the diary was likened to a think tank and space to ventilate feelings, and a help to discover patterns and better understand the self and the patient. The latter made it easier to communicate with others, possibly resulting in an interpersonal value.

Writing for an Audience

The diary instructions (papers IV-V) motivated users to explore the depression’s influence on their life, including their personal relationships, stimulating the writing process. Several participants worried about the patient or someone else reading their writings, which may have influenced the writing process. Loyalty concerns and fear of hurting or divulging the persons concerned may hinder free writing. This problem was addressed through encryption and password protection of the diary and forum. One participant mentioned sometimes having
the patient as an audience in mind when writing in the diary and addressing the contents to the ill person, regardless of the subsequent decision to share the writings or not.

Writers have shown to be influenced by imaginary readers or audiences while writing, more than by the anticipation of real people’s reaction, whether fully aware or not of the reader that he or she has in mind during the writing process (Hunt, in Bolton et al. 2004). The exercise of writing while thinking of a special person was useful in identifying and rehabilitating unresolved family relations, in redressing an imbalance in the relationship with an inner critic, and in clarifying writer identity.

In the forum, members are writing for an audience with persons with similar problems; however integrity concerns influence the contents through the exclusion of personal information that can lead to identification. Previous research shows that electronic support group users tend to provide legitimacy for seeking and receiving help online, for instance through the provision of a short narrative (i.e. information about diagnosis and received treatment) when posting to a support group (Galegher et al. 1998). The attempts at legitimacy and authority in social support groups can be strategies to strengthen the community and group membership, showing its members that they are not alone in their situation, which in itself seems to be an important point when seeking support online (Galegher et al. 1998).

Integration of Trustworthy Online Information and Services in Care
A number of international organizations work with qualitative issues related to health information online. But whose responsibility is it to overview and ensure the trustworthiness of health information and services online and to introduce them among the regular health care services? Is the mental health sector ready to embrace web based support alternatives? The promising results and implementation of online therapies (CBT) for depression (Andersson et al. 2005; Andersson 2008; Kessler 2009) show that the Internet is making its entrance within the psychiatric system. Presently, CBT online appears to be a dominating trend. Its way into the mental health sector speaks for a certain acceptance of the technology amongst health professionals and patients. Other support alternatives and schools within psychiatry may also benefit from this technology to make their way both to patients and their families. The National Board of Health and Welfare in Sweden recently recommended CBT and conversational therapy as the primary treatment alternatives against depression, rather than pharmacological treatment. However, these recommendations raised the psychiatric core’s protests, illuminating the current debate on the treatment of depression (Atterstam Sep. 2009).
Modern technology should be adaptable to practitioners’ different theoretical frameworks (i.e. psychodynamic, humanistic-existential, cognitive-behavioral), enhancing its practical use in mental health care (MCH) interventions (Coyle et al. 2007). The designed systems should be adaptable to different theoretical backgrounds, mental health disorders, demographic groups and specific needs of individual clients. While psychodynamic approaches have not received much attention in relation to computer assisted intervention research, cognitive behavioral approaches do. With an approach that is highly structured, goal-oriented, problem solving, easily learned and less time consuming than other methods, CBT is interesting to computerize (Coyle et al. 2007). With roots in learning theory and behavior theory, CBT aims at cognitive restructuring.

Humanistic-existential approaches to mental health interventions (MHI) aim at personal empowerment, with individuals gaining personal power and control over how they live (Coyle et al. 2007). Humanistic approaches also entail narrative psychotherapy, in which storytelling is a tool for communication and personal understanding. As seen with the inhibition theory, traumatic experiences that are not socially acceptable may lead to social isolation through inhibition. In this context, computerized MHI can be an alternative medium for the creation of narratives (Coyle et al. 2007).

Coyle et al. (2007) illuminate the importance of cooperation between human-computer interaction (HCI) designers and MHC researchers to reach practical systems for intervention. As seen in the present project, cooperation with users is equally valuable to map usability requirements. Relatives’ needs and wishes related to a daily life with depression were explored and used as base in the development of the website.
Conclusions

The present work (papers II-III) points to a lack of attention and support towards families living with depression, corroborating previous research (i.e. Östman 2000; Jones 2002). A number of different initiatives stemming from diverse actors and addressing depression issues can be found on the Internet (paper I). Informational websites, online cognitive therapy and self assessment questionnaires are example of this. Nevertheless, many of these initiatives are for patients. Little attention has been focused on families, which is the target of the present project. Information is a prerequisite to discover and hence treat depression, making the relatives an important target for informational campaigns. A person with depression may not have the insight or energy to actually seek help. Other feelings, such as shame and guilt, may be barriers to seek treatment. The stigma around mental illness is still strong, although some positive changes have been noticed over the last decade.

Iterative design, including close cooperation with potential users of online systems, is an essential ingredient in the development of web based tools. The current self-help tool is a result of such cooperation (paper IV). The exploration of users’ experiences shows interesting results (paper V) that can be further explored. Motivations and obstacles to using online self-help tools are illuminated and show areas that need special attention from developers, i.e. privacy issues. The motivations reflect some of the known advantages of computer mediated communication (CMC), such as convenience of use and the appeal of anonymity. The website appears to fill a number of useful functions, allowing its users to actively deal with their feelings and meet similar others that can offer support through the exchange of stories (paper V). As shown previously, online support may fulfill certain needs of support and, at times, compensate for poor support offline. Participants reflect a process of growing openness about the presence of mental illness in their life. They appear empowered by their partaking and use
of the website, which can be beneficial not only to themselves, but also to the patient and others in similar situations. It can be a step in fighting the stigma surrounding mental illness.

The growing amount of persons using the Internet as a daily tool is a central incentive to explore the advantages and drawbacks of this technology as a medium for health care. It is essential to understand its potential, but also if and how it can do harm, and how this can be prevented. The latter requires awareness from health care professionals that regularly meet patients that are also online health seekers. Hopefully, this thesis has helped in getting an overview of the e-health field in relation to depression and an insight into the potential of the Internet as a health care tool in this context. This project also illuminates the relatives’ wishes for specific information online, such as tips on books, articles and cultural events related to depression and advice from professionals, pointing to areas that can be further developed online.

Clearly, families living with mental illness need support to cope in their daily life with depression. An informed and empowered relative may be in a better position to help the patient. Supporting relatives is also an essential step in preventing further mental health problems and additional costs to society. The Internet’s potential as a health care tool needs to be further explored. A continued development and assessment of the present tool may enhance its usability. Further research is necessary to appraise its value on a larger scale over time.
The aim of the present thesis was to explore families’ experiences of living close to a person with depression and the Internet’s potential as a health care tool. The project resulted in http://www.sommarregn.se, a website aimed at supporting relatives in their daily life with depression. The fourth study (paper IV) showed that an iterative design process in close cooperation with potential users was a constructive design to actively involve users and explore their wishes and requirements. Close cooperation with a web expert was a prerequisite to achieve the set goal. The fifth study (paper V) showed that the website fulfills a number of valuable functions for its users and illuminates possible areas for enhancements of the website. The tool appears to be an interesting alternative to support relatives and a further development and assessment of the website may enhance its usability. Further, the tool should be developed in cooperation with health care professionals to assess its clinical value. The tool can be further developed, based on feedback from the participants in the last two studies (papers IV-V) and a future version may include further services, addressing the relatives’ needs and wishes.

The present qualitative studies ought to be followed by quantitative studies, in which the tool can be tested and evaluated with larger samples and possibly with different targets. If the website is useful for families living with depression, it may be valuable for individuals living with other difficulties. It would be interesting to see if the concept is applicable to wider and differing populations. Bragadottir (2008) supports a variation of research methods, including both qualitative and quantitative approaches to map the most efficient structure, process, outcome and participant of computer mediated support groups (CMSG). While interviews can shed light on participants’ needs and expectations, observations can help find the most beneficial structure and process to provide optimal support through CMSGs (Bragadottir 2008). The empowering and disempowering processes and outcomes in support groups online should be further explored to maximize their
potential benefits and prevent harm.

Diaries and autobiographies have been used as research method within different disciplines such as anthropology, historical and feminist research, and eventually within the social sciences. Diaries have shown potential in health service research, allowing to record events over time, as close as possible to their occurrence (Elliott 1997). Depending on the diary format, the diarist’s frame of reference can also be captured, for instance with the diary-interview method that can capture otherwise muted voices (Elliott 1997). This method offers an insight into how illness experiences are constructed and allows the diarist to reflect on and analyze what is said through participation in the research process (Elliott 1997). Diaries have for instance been used to gain insight into self-care (Freer 1980), giving access to knowledge that may have passed unnoticed with another data collection method and research approach.

The writings in the forum and diaries on http://www.sommarregn.se can thus be valuable research material. The relatives’ situation can be further explored, as well as their experiences of using the website. However, the diaries are private and encrypted. Access to and research on the material naturally requires permission from the authors. In the present project, all participants gave their permission to use the writings in the forum as research data. Nevertheless, further research on material from online communities requires a discussion of the private versus public character of the material and an ethical handling of data.

Consideration towards the potential benefit and harm to the studied population needs to be taken in every new research project online. The principle of informed consent in online research may however need to be re-evaluated in today’s society, where the Internet is so integrated in everyday life (Daneback 2006). Daneback (2006) suggests confidentiality (no disclosure of personal identifiable information) as an ethical approach to research on online material; material that may be considered as public despite the possibly private character of its contents. Nevertheless, the material in the diaries on http://www.sommarregn.se has to be considered as private and the authors’ permission is a prerequisite to access the material for research purposes.
Not only the patients, but even their families need support to cope with mental illness and its consequences on daily life. Health care professionals need to be informed about the Internet’s potential and drawbacks as a health care tool in order to address these issues with their patients and their families. Healthcare providers’ reaction to patients’ participation in online support groups appear to be mixed, with both receptive and reluctant attitudes being reported by users (Coulson and Knibb 2007). An open climate to discuss uses of the Internet as a health care tool is necessary for a constructive dialogue between health care professionals and patients and their families. The Internet offers a vast array of health information and services of differing quality. While constructive and qualitative information and support online can be an asset to prevent ill health, destructive and incorrect information can have negative, and possibly life threatening consequences. Misinformation and online groups supporting self destructive acts are examples of this. Such problems are a reality that needs to be acknowledged.

The economy is under high pressure and resources for mental health care are limited, not to say scarce. A growing amount of the worldwide population is using the Internet as a health care tool. Therefore, viable support alternatives, such as online support, should be further explored to work as a complement to regular health care. Online services shall not replace or eradicate regular health care or face-to-face meetings; however, their potential to address the needs of targeted populations in a cost effective way should be explored. The latter is an aspect that needs to be further assessed in future studies. Health professionals are in a key position to refer patients and their relatives to alternative sources of support. A prerequisite to such referrals is the awareness of their existence and knowledge about their quality and effects. Cooperation with health care professionals is also important for the further development of digitally based tools to assess their value from a clinical perspective.
Avhandlingens titel är “Design av nätbaserat stöd till familjer som lever med depression”. Avhandlingen innehåller studier av e-hälsolandskapet i förhållande till depression. Med e-hälsa menas att Internet används som mötesplats för kommunikation och utbyte av hälsoinformation och tjänster. Avhandlingen visar hur utbudet ser ut avseende nätbaserat material och tjänster relaterade till depression, med särskilt fokus på information och tjänster som vänder sig till anhöriga. Den visar att många olika aktörer finns representerade på Internet med olika initiativ, som exempelvis nätbaserad kognitiv betende terapi, nätgemenskaper kring depressiva sjukdomar och hälsoinformation som beskriver vanliga depressionssymtom. Vanligast är att dessa initiativ främst vänder sig till patienter och inte till anhöriga, som visar sig ha egna behov av stöd och information som sällan tiltgodoses av vården.

Avhandlingen innehåller en studie om anhörigas situation, deras erfarenheter av att leva nära en person med depression, samt deras behov av stöd och information. Denna studie visar att anhöriga kan uppleva en tilltagande känsla av att inte leva sitt eget liv. Detta beror på svårigheter att balansera relationer, på en process där anhöriga omvärderar sina livsomständigheter och anpassar sig till situationen, och på svårigheter för anhöriga att bli sedda och hörda inom vården. På så vis lever många anhöriga i skuggan av depressionen.

I en situation där resurser till hälsorelaterat stöd är begränsade är det särskilt viktigt att undersöka alternativa stödmöjligheter för utsatta grupper, samt nätets potential som hälsoverktyg. På så vis kan nätets styrkor tas tillvara och faror blir belysta. En studie i avhandlingen undersöker motiv och hinder för användandet av nätbaserade verktyg bland en grupp anhöriga. Det visar sig att Internet har egenskaper som kan vara fördelaktiga i samband med utvecklandet och användandet av självhjälpstverktyg. Exempel på fördelar är


Mötet med medmänniskor kan förenklas och förstärkas med hjälp av nätbaserade tjänster, framförallt för personer som är hämnade av sitt sjukdomstillstånd eller isolerade på grund av sitt geografiska läge. Tanken är dock att nätbaserade tjänster ska fungera som ett komplement till sedvanlig sjukvård och inte ersätta kontakter ansikte mot ansikte. Det är viktigt att hälsopersonal är medveten om och insatt i nätets utbud av tjänster, samt dess för- och nackdelar. I dagens IT-samhälle är en öppen dialog mellan hälsopersonal, patienter och anhöriga kring nätets användning i hälsorelaterade sammanhang önskvärd, dels för att utnyttja nätets potential, men framförallt för att främja medborgarnas hälsa.
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