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COPING ONLINE

PATIENTS' USE OF THE INTERNET

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ABSTRACT

Taking the perspective of the individual, this thesis addresses the increasing use of Internet by patients seeking information and connections to cope with a new life situation caused by chronic illness. The main objective is to understand and conceptualize this use of the Internet. A qualitative study of 7 patient associations, 15 patient self-help groups and 18 individual patients comprise the empirical data. Parkinson's disease, Multiple Sclerosis, Whiplash injury, and Prostate cancer exemplify medical conditions represented in the studies. By drawing on *coping theory*, further developed by means of theoretical constructs related to studies on information behaviour and online interaction the work adds a perspective on information technology use related to psychological reasoning about how individuals manage stressful situations like facing chronic illness. The findings show that patients' use of the Internet can be understood as means to cope with a difficult life situation, the particular problem (the illness), and the related emotions. The main implications from this study for the development of Internet use in the patient-healthcare relationship suggest that the design should consider patients' requirements for *flexible and personalized Internet solutions*, development of spaces for *online dialogues, general as well as specific medical information*, and to provide professional *online guidance* to relevant and reliable medical information. For healthcare practice, the main implications are *to increase healthcare's Internet awareness and online participation*. Additional implications concerns the development of *well-informed patients*, acting as both *users and producers* of medical information, putting *additional technological demands* on healthcare's Internet use, and strengthening their position to *challenge the medical expertise*. Further, coping online accentuates the issues of *digital/medical divide* where some individuals strong on resources get access to healthcare on different conditions than others.

Keywords: *Internet, users, patients, medical information, self-help, healthcare practice*

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*Ulrika Josefsson
Sandhult
January 2007*

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Part I

THE SUMMARY

1. INTRODUCTION

This thesis is about chronically ill *Patients' use of the Internet* and addresses the radically new ways patients¹ may approach their situation in the early 21st century.

Facing chronic illness often involves difficult changes in life and new situations that demand the individual to cope in one way or another. This may concern medical, social or practical matters of life being affected by the illness. Patients meet these challenges in different ways, and with access to the Internet, an additional approach is offered that is gaining more and more interest (c.f. Hardey, 1999; 2001; Johnson & Ambrose, 2006; Kivits, 2004; Murero & Rice, 2006).

The increasing use of the Internet for healthcare related purposes serves as an important point of departure for this thesis. Even though facts and figures vary between (western society) countries the trend shows an increased Internet use for medical information among private individuals (Fox, 2005; Statistics Sweden, 2005). In addition, the number of web sites offering health related information is increasing (Eysenbach & Köhler, 2002, Morahan-Martin, 2004; Murero & Rice, 2006). Today, numerous sources online offers medical information and social interaction provided by private as well as public actors like patient associations, pharmaceutical companies, public institutions, medical research centres, hospitals, universities, private individuals, and so on.

When facing chronic illness the Internet thus offers patients many alternatives for information and communication making this a complex phenomenon to comprehend. Nevertheless, to be able to cultivate the opportunities and to deal with the challenges it may bring, there is a need to learn about the nature and dynamics of the phenomenon. Also, the fact that Internet use for health purposes concerns many people and that chronic illness is something that can strike any one of us makes this a significant research area. This is further emphasized by the intuitive connection between patients' use of the Internet and healthcare practice being a major institution in society. Additionally, patients' use of the Internet constitutes a relevant example of how individuals make use of IT (Information Technology) in their everyday live.

The development of an increased use of the Internet for health related purposes is however not an isolated phenomenon. Two ongoing processes in society exemplify this. The first process concerns the increasing use of information technology in areas related to people's private life. With the

¹ In the context of this thesis the concept of patient refers to a person who is diagnosed with a particular chronic illness having recurrent contacts with the treating clinic or doctor. In section 2.2 I further address my understanding of the patient concept.

development and diffusion of the Internet, this process has taken a great leap with Internet use for almost all aspects of our lives.

The second process refers to the changing role of the citizen moving towards increased personal responsibility and freedom of choice. Earlier the patient was recognized mainly as passive, receiving and accepting whatever treatment and medication suggested by the doctor. Medical professionals held the expertise about the condition, what measures to be taken, and possible alternatives. In contrast, the ongoing development of the patient role recognizes the idea of the patient as an informed partner, taking active part in healthcare decisions.

Each process has its own course of development but regarding chronically ill patients' use of the Internet, it is fruitful to consider them connected and interrelated. For instance, to meet the demands of the role as an informed partaker, patients need various kinds of easy accessible information. Here the diffusion of the Internet plays an important role offering medical facts as well as emotional support on a 24 hour basis. Simultaneously, the access to medical information triggers patients and the general public to put new demands on healthcare and professionals regarding service delivery.

In addition, there are great expectations on Internet use to support healthcare practice meeting some of the future healthcare challenges related to finances, demography as well as increasing demands on technology adoption (Wen & Tan, 2003). An important guiding principle for the development of technology in this area is to design for "patient-centeredness" (Leonard et al., 2003) referring to patient driven (as opposed to institution driven) technical solutions (Demiris, 2006). With these leading ideas and the ongoing processes mentioned it is therefore relevant to explore what healthcare practice and IT developers might learn from patients' use of the Internet when coping online.

1.1 RELATED RESEARCH

In general, this thesis relates to research studies aiming to understand IT use in people's lives outside the traditional IS (Information Systems) context of organization and work life. These studies contribute with additional perspectives on IT use exploring technical, social, political and personal driving forces of the diffusion of IT use and related opportunities and challenges for the individual and her² social context. Additionally, in a shorter or longer time perspective these studies aim to contribute to further improvements of information technology and its use.

More specifically, the thesis relates to studies of *Internet use in everyday life*. Examples of research in this area focus on the forming and maintenance of social relationships in online group environments (like chats, bulletin boards, and

² In order to simplify reading I use the term "her" when referring to either woman or man.

e-mail lists) (Baym, 1995; 1998; Preece, 2000; Sveningsson, 2001; Smith & Kollock, 1999; Mynatt et al., 1999; Wellman & Haythornthwaite, 2002). Other examples are studies focusing on individuals' online information behaviour (Burnett & Burkle, 2004; Hektor, 2001). Additional studies explore the mechanisms of Internet diffusion in everyday life (Cummings & Kraut, 2002) and the social consequences of this development (Katz & Rice, 2002; Kraut et al., 2002).

Research on Internet use in everyday life rarely addresses issues related to the specifics of facing chronic illness and how it relates to patients' Internet use. Since this represents an emergent form of IT use in our contemporary society related to highly relevant areas in our lives, like personal health and healthcare practice, it deserves our attention. Here, this thesis contributes with a comprehensive picture aiming to increase our understanding of patients' use of the Internet as an online phenomenon.

In addition, previous work mainly explores Internet use in everyday life from social, technical and/or cultural perspectives. Here, this thesis adds a perspective on Internet use as it considers patients' use of the Internet in the light of psychological reasoning about how individuals manage stressful situations. In particular, this means that the work has a theoretical contribution as it adopts ideas from coping literature (Lazarus & Folkman, 1984; Folkman & Moskowitz, 2004; Snyder, 1999). This perspective contributes with an increased understanding of human behavioural processes that might influence the way we understand IT use (Beaudry & Pinsonneault, 2005).

An additional area of related research focuses on Internet use for healthcare purposes. Firstly, this concerns *Internet use in healthcare practice*. Examples are studies focusing on the support of the Internet for information and communication between healthcare and the patient (Demiris, 2006; Murero & Rice, 2006). An example in this area is Gruca & Wakefield (2004) who studied the fit between the information available on hospital web sites and patients' requirements. Another example of this type of studies is the work of Doupi & Van der Lei (2002) and their analysis of how the electronic patient record support Internet based communication between healthcare and the patient enhancing patient education and participation. Additional research focus on how Internet can be used in treatment situations (Carlbring & Andersson, 2006; Kummervold et al., 2002; Shaw et al., 2000). For example, emphasizing technical design aspects, Leimeister et al (2004) analyze the use of a healthcare managed online support groups for breast cancer patients.

Secondly, related studies in this area concern research on *individuals' use of the Internet* for healthcare purposes. Examples of related work focus on how health seekers in general seek medical information on the Internet (Kivits, 2004; Morhan-Martin, 2004). Eysenbach & Köhler (2002) found that individuals seeking online medical information pay little attention to certificates or ethical codes aiming to guarantee the trustworthiness of the information. Instead,

seekers trust their own preferences when judging the information found. Similarly, Henwood et al. (2003) found low awareness among the participants about how to judge different Internet sources and how to technically make their way on the Internet. Additionally, the authors emphasize that not all patients want to seek online information even though they were familiar with the seeking procedures.

Additionally, studies in this area concern individuals' social interactions online for healthcare purposes (Finn, 1999; Johnson & Ambrose; 2006; Loader et al., 2002). Maloney-Krichmar & Preece (2005) provide a rich picture of the social dynamics of an online self-help group. The authors conclude that in order to develop the group, several factors should be considered such as technical support for formation of subgroups, development of group norms, moderator role, and the need for guidance to reliable information sources online. Other researchers like Lester et al. (2004) focus on technical aspects of patients' organizing of self-help tools. The authors conclude that by studying patients' forming and managing the support contribute to an increased knowledge about the complicated structure of how patients reach out and connect with others.

Related research on Internet use for healthcare purposes directs the attention to several issues critical to the development of our understanding of patients' use of the Internet. However, few studies approach Internet use from a *patient perspective* (c.f. Demiris, 2006; Johnson & Ambrose, 2006; Morahan-Martin, 2004; Murero & Rice, 2006; Rice & Katz, 2001; Wilson, 2003). Despite previous research efforts, we still have limited knowledge of individual driving forces making patients go online, and we know little of what characterizes the online paths patients follow and the meeting places they create. Further, earlier studies pay little attention to the dynamics and development of patients' activities online. Here, this thesis contributes with a broad introductory picture of patients' movements online and how this relates to the facing of illness, the patient role, the relationship with healthcare, and future technology development. This is important knowledge supporting our understanding of the meaning of this particular form of Internet use for the individual, for healthcare practice as well as for the design of future Internet use.

1.2 RESEARCH AIM AND QUESTIONS

The aim of this thesis is *to understand patients' use of the Internet*. This aim is motivated by my ambition to capture an emergent phenomenon of individual IT use with immediate interest and implications for technology development and social practice. Departing from the outline above, my research broadly approaches the characteristics of the patient situation, their online actions, and motivation to go online. The work starts out from the individual patient but reaches towards group activities and traces on the level of society.

Consequently, the main research question in the thesis is: *how can we understand patients' use of the Internet?* Further exploring the phenomena the main question is divided in three sub questions:

- *How can we problematize and conceptualize patients' use of the Internet?*
- *What are the implications of patients' coping online for the design of Internet use in the relationship between healthcare and patients?*
- *What are the implications of patients' coping online for healthcare practice?*

These questions mirror my intention to follow patients to capture what occurs in the online spaces they visit. In addition, the questions reflect the idea to learn from their experiences of technology use in private life in order to contribute to the development of new technology use in and healthcare practice.

1.3 THE PAPERS

- 1 Josefsson, U. (2006a). Exploring E-patients' heterogeneity: Towards personalized E-health applications, In *Proceedings of the 14th European Conference on Information Systems*, June 12-14, 2006, Göteborg, Sweden.
2. Josefsson, U. (2006b). Patients' Online Information Seeking Behavior. In M. Murero, & R. E. Rice (Eds.) *The Internet and Healthcare: Theory, Research and Practice*, Mahwah, NJ: Lawrence Erlbaum Associates.
3. Josefsson, U. (forthcoming). Patients' initiation of self-help groups on the Internet: A coping perspective. Submitted to the *European Journal of Information Systems*.³
4. Josefsson, U. (2005). Coping with Illness Online: The Case of Patients' Online Communities. *The Information Society*, 21(2), 143-153.⁴
5. Josefsson, U. & Ranerup, A. (2003). Consumerism revisited: The emergent roles of new electronic intermediaries between citizens and the public sector. *Information Polity*, 8(3-4), 167-180.

Table 1. The papers included in the thesis.

³ An earlier version of this paper was presented at the HICSS conference, in Hawaii, 2004: Patients creating self-help on the Internet - lessons for future design of Internet based healthcare resources. In *Proceedings of the 37th Hawaii International Conference on System Sciences*, 5-8 January 2004.

⁴ An earlier version of this paper was presented at the International Conference on Communities and Technologies, in Amsterdam, 2003: Patients' Online Communities – Experiences of emergent Swedish self-help on the Internet. In M. Huysman, E. Wenger & V. Wulff (Eds.) *Communities and Technologies*. In *Proceedings of the First International Conference on Communities and Technologies*, pp. 369-389, 19-21 September 2003, Amsterdam.

1.4 THESIS STRUCTURE

The following section (section 2) describes the patient situation when facing illness in relation to the patient role, medical condition, contact with healthcare as well as the emergent use of the Internet in healthcare. Section 3 describes the research process and the research context presenting patient associations, online self-help groups, and patients as the target of my empirical data collection and analysis. Section 4 presents the theoretical ideas of coping and the components of my proposed “model of coping online”. This is followed by section 5 presenting the results and research contributions as well discussions on the implications for the design of Internet support in the patient–healthcare relationship as well as implications for the healthcare practise. Section 6 closes part one of the thesis providing conclusions of the work. The second part presents the five papers that together with the summary part constitute this thesis.

2. FACING ILLNESS

Facing illness is often a difficult and stressful situation for the individual and her family and friends. It involves processes related to medical aspects of the specific diagnosis as well as the individuals’ behavioural responses (Morse & Johnson, 1991). Typically, it starts with a stage of uncertainty where the individual suspects something is wrong moving through phases when medical contacts become necessary and the individual might relinquishes control and withdraw her self. This is followed by stages where the individual strives to regain self and wellness (ibid.) by trying to make sense and find ways to cope with the situation (Lazarus & Folkman, 1984). These processes of facing illness are a part of the overall picture of patients’ use of the Internet although different type of diagnoses put different demands on the individual. Therefore, the following sections aim to clarify the particular patient group at focus and the characteristics of the role as a patient that the individual takes on. In addition, the following illustrates the Swedish healthcare system meeting the patient. The concluding sections introduce the Internet applications used by the patients and the characteristics of the present use of the Internet in the patient – healthcare relationship.

2.1 THE CHRONIC ILLNESS

The thesis focuses on patients suffering from various *chronic illnesses*. This demands some remarks on the use of the concepts. First, to define *chronic* illness is difficult. There is no agreed upon definition of the concept and the conditions have varying causes, courses, changeability, and consequences (Maes et al., 1996). However,

starting with the etymology of the concept, chronic comes from the Greek term of “chronikos” meaning “of time” and from “Chronos” said to be the personification of time. In addition, the dictionary (Merriam-Webster Online, 2006) says chronic means “*marked by long duration or frequent recurrence, not acute*”. The time perspective and durability is thus central features of the concept. A frequently used definition of chronic illness provided by The National Health Council in the USA (Fox, 1957⁵ as cited in Nordenfelt, 1995) emphasizes this. The definition states that chronic illnesses “*are permanent, leave residual disability, are caused by non-reversible pathological alteration, require special training of the patient for rehabilitation, may be expected to require long period of supervision, observation or care*” (p. 290). In similar way, Maes et al. (1996) describe what usually makes a condition considered chronic: its prevalence and/or longevity, high cost, and mortality. Here, however conditions might be considered as chronic even if not permanent in a strict sense. This means conditions can be treated as chronic although they are not strictly irreversible but long-enduring diseases (Nordenfelt, 1995).

Second, the concept of *illness* is preferred in this thesis in order to widen our conception of the patient situation. In the philosophy of medicine, several distinctions are made between the concepts of illness and disease (Nordenfelt, 1995; Maes et al., 1996). Usually disease refers to the particular diagnosis and physiological malfunction. On the other hand, illness involves the persons’ situation at large (Brülde & Tengland, 2003; Nordenfelt, 1995; Morse & Johnson, 1991). This refers to “*individuals and their families as they make sense of, respond to, cope with, and adapt to symptoms and disabilities*” (Morse & Johnson, 1991, p. 2). However, this distinction between the concepts was not clear to me in the early stages of my research work. As a result, some of the papers treat the concepts as synonymous. Therefore, the reader is advised to pay attention to the particular context (the personal medical context or the larger context of the patient situation) to grasp the appropriate concept.

A general ambition with this thesis work is to provide a *comprehensive* picture of patients’ online activities. To discover variations, patterns, tendencies, and dimensions this call for studies of patients with the potential of long time use of the Internet. The nature of chronic conditions brings such potentials for the patients using the Internet. Further, the choice to focus on patients with this type of diagnosis is motivated by chronic conditions constituting a major problem in our contemporary society and that there are indications of increasing prevalence (Maes et al., 1996, Nordenfelt, 1995; Snyder, 1999). Further, the long time perspective could make patients with chronic conditions an important group to support with Internet based healthcare resources for disease management and contact with healthcare providers.

⁵ Fox, J. (1957). *The Chronically Ill*, Philosophical Library, New York.

2.2 THE PATIENT

In general, we might consider someone applying for healthcare as a patient. In Sweden a recommended use of the concept state that a patient is a “*person who is receiving or is registered to receive healthcare*” (author’s translation) (National Board of Health and Welfare, 2006). However, other descriptions (like in preliminary work of proposed bills) the meaning is widen to involve all individuals that regarding their own health condition have contact with healthcare, which in fact would involve also a healthy person (Arvhill & Sverne⁶, 2000 as cited in Nordgren, 2003). In the dictionary, however, a patient is someone with a form of health problem and “*bearing pains or trials calmly or without complaint*” (Merriam-Webster Online, 2006). Since there is no universal definition of the patient concept, I acknowledge some descriptions’ emphasis on contact with healthcare and a confirmed diagnosis. That is, in this thesis I refer to a patient as *a person who is diagnosed with a certain chronic illness having recurrent contacts with the treating clinic or doctor*.

An additional way to view a person facing illness is to consider the role as a patient that she is assuming. Earlier, subjection to the monopoly of the healthcare’s and doctors’ professional expertise and knowledge strongly characterized the patient role (Hardey, 1999; Saltman, 1994). The patient was supposed to obey the doctor’s orders and to follow the advice given. It was not until the 1960ies that the patient as an active individual attracted attention. During the 1970ties this interest further developed and a changed view of patients started to develop focusing on patients’ abilities to take initiatives and to care for simpler complaints on their own (Nordgren, 2003)

Since then the development towards a more empowered and self-determined patient has continued (Saltman, 1994) and lately concepts of “the informed patient” or patients as “partakers” (Hardey, 2001; Henwood et al., 2003) are common in the debate. However, the emergent role of the patient as active and informed involves several dimensions. For instance, there is the patient as a competent *healthcare consumer* ready to critically examine, take position and make choices of care and healthcare providers. Also, there is the patient as a *cooperating partner* working together with healthcare professionals making medical decisions. Further, the patient comes as an *expert patient* seeking information, learning and becoming knowledgeable about her own particular case of illness. However, an important requirement for the emergent patient role is the access to correct and adequate information. Without easy access to reliable and relevant information, there are obvious difficulties for individuals to act the informed patient. Here the Internet plays a significant role with easy accessible medical information of different kinds. In addition, several reports illustrate that the past years show a tremendous growth in people’s use of the Internet for medical information (Fox, 2005; Statistics Sweden, 2005). Therefore, an additional dimension is to consider

⁶ Arvhill, E. S. & Sverne, T. (2000). *Patientens rätt*. Stockholm: Nordstedts juridik.

patients also in terms of *information technology users* adopting technology to manage their diseases and overall patient situations.

This development of the patient role forms the background of patients' meetings with healthcare. Even though it is clear that not all patients have the necessary resources and/or motivations to live up to this new role, the demands on the healthcare and patients is still affected by this development (Henwood et al., 2003; Hardey, 1999; 2001; Rice & Katz, 2001).

2.3 THE HEALTHCARE

In short, when facing illness the initial contact with Swedish public healthcare is often made through the primary care units at outpatient clinics. First, the patient meets a general practitioner. The patient is then treated and/or referred to a medical specialist at a local hospital. After examinations and treatments at the specialist clinic (and contacts with other healthcare professionals and units such as physiotherapists, dieticians, laboratory assistants, X-ray unit, and so on) primary care units (sometimes the general practitioner) manage the continuing contacts. In case of acute conditions, the patient is taken in through emergency units for institutional care.

Thus, getting in contact with the healthcare involves the meeting with a complex organization divided in different areas of competencies and professions. In short, Swedish healthcare systems is built on local authorities (County Councils) having the main healthcare responsibility in their geographical area. However, highly specialised care is organized and planned on a regional level. For particular functions, the responsibility has been taken over by the local municipalities. This is true for long-term geriatric care, mentally disabled and some other handicapped groups (Calltorp, 1999). Also, a guiding principle is that the healthcare in Sweden is publicly financed (Falk & Nilsson, 1999) through local taxes and central government contributions. There is a trend, however, that the private share is increasing (Calltorp, 1999). At the same time this trend shows signs of increased cooperative efforts between private and public actors (Falk & Nilsson, 1999).

However, the healthcare is facing a number of challenges influencing how the meeting with the patient can take place and how it can be formed. Some of these future challenges are related to finances, demography as well as increasing demands to adopt new technology (Wen & Tan, 2003). The finance factor relates to limited budgets together with concurrent demands to maintain full service and quality. Second, demography concerns the expected development of an aging population with more people living longer, which is believed to involve increased pressure on healthcare delivery. The development of new technology is the third factor involving demands on healthcare from society and citizens to adopt new technology for information and communication. These challenges contribute to

the development of new forms of healthcare management contrasting the predominant forms like bureaucracy control and official procedures (Falk & Nilsson, 1999). Some of these new forms of management relates to the more general ideas of marketization in public society. This is true in areas of public service like telecommunication, public transportations and postal service also expanding in areas like education and healthcare (Nordgren, 2003). Among other things, this involves a changed discourse where the patient is transferred to a customer provided possibility to make choices influencing the “healthcare market”. This development should be viewed in relation to a parallel ongoing process in public society characterized by the idea of the individual’s self-determination and democratic right to make choices regarding public services also.

2.4 INTERNET APPLICATIONS USED BY THE PATIENTS

Addressing Internet use when facing illness deserve some attention to the Internet applications used by the patients. However, first I would like to pay some attention to the understanding of the concept of the Internet applied in this thesis. In a brief technical sense the Internet is a web of computers and computer networks connected through TCP/IP⁷ protocols. This means the Internet is actually a transportation system for information stored on the connected computers and not the available information per se. However, during the 10-12 years that the Internet has been available for the general public (in western society) there has developed a common understandig of the concept, more related to technology use than the technical structure (c.f. Braa et al., 2000; Wellman & Haythorntwaite, 2002; Preece, 2000; Smith & Collock, 1999; Rice & Katz, 2001). In short, this view of the Internet emphasizes aspects such as global access to information of different kinds, numerous possibilities for social exchange, and a computer mediated space for various types of private transactions (like shopping, banking business or contacts with public authorities). This understanding of the concept characterize the use of the Internet in this thesis as well. In addition, it is only for the sake of variety in the text that I use the term “online” as synonymous to the Internet.

Having said this, there are numerous software applications available supporting users in their access of information and interactive facilities on the Internet. The particular applications used by the participants in this thesis involves the same applications used by individuals for other Internet purposes. For instance, the participants used regular search engines like Google, Altavista, and Yahoo to navigate the Internet in general. Similarly they used common e-mail systems (like Netscape, Outdoor Express, Eudora Email, Yahoo Mail, and MSN Hotmail) to communicate. This form of asynchronous communication was

⁷Transmission Control Protocol/Internet Protocol

further supported by systems for bulletin boards. Occasionally the patients used chat systems for synchronous communication with fellow sufferers.

When creating personal homepages some patients use applications available for free on the Internet while others spent private means to get the necessary software. Examples of applications used by the patients are FrontPage, Claris Homepage, and Dreamweaver. In addition, the physical location of the web pages varies. For example, some have their web pages located on free servers in exchange for commercial advertising while others pay for a web hotel to avoid this. Additionally, there were patients who had bought their own domain names.

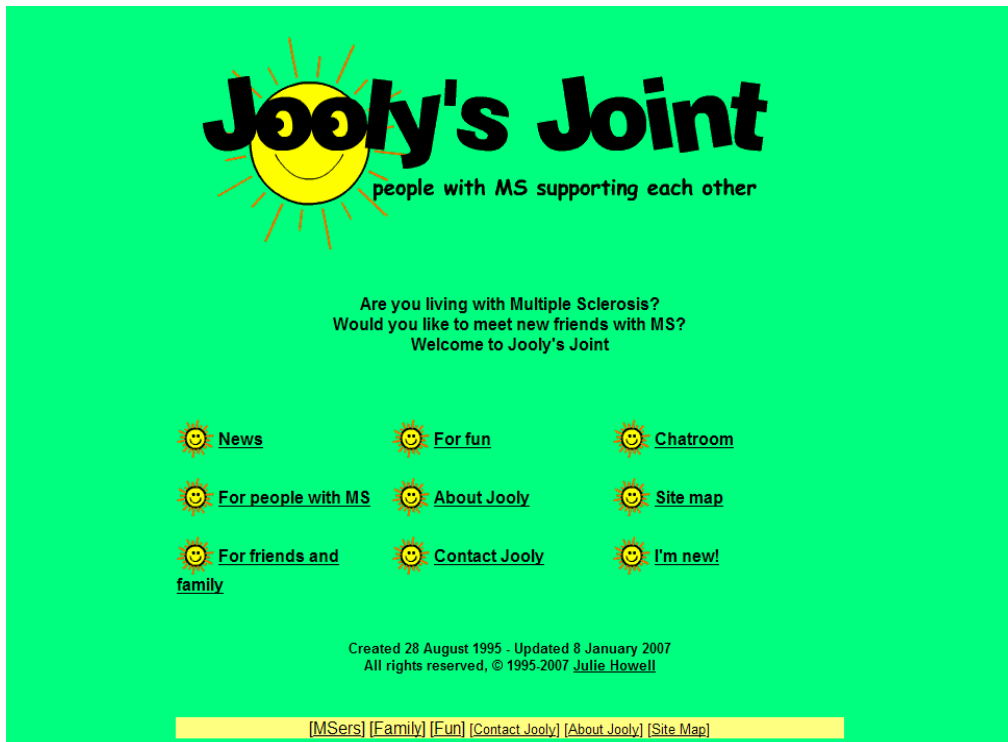
However, using the Internet patients encounter different web pages produced by various actors (like hospitals, county councils, pharmaceutical companies, patient associations, medical journals, private individuals, and so on). This involves different demands to manage form as well as content. For instance, the patient as a user should handle information seeking procedures as well as interactive facilities like chats and e-mail. Also, she should be able to judge the information (in Swedish or in other languages) from various (professional or lay) sources. To *exemplify* the variation and to briefly introduce the reader to some Internet use for medical information the screenshots below show a few types of web sites used by patients.



Screenshot illustrating the web site www.sjukvardsradgivningen.se⁸ produced by Swedish County Councils in cooperation with the Swedish pharmacy chain Apoteket.

The screenshot above illustrates a particular form of web resource that I refer to as health portals. The main purpose of the health portals are to serve as a major starting point for health information seekers on the Internet. The portals are collections of web pages produced by public or private healthcare actors offering the visitor several facilities. For instance, they provide information on various areas related to different diagnoses, treatments, and forms of medication. Additionally, there are general health information and information about patients rights. Also, the healthportal offers possibilities for contact with health professionals for further information and advice. Only in a few cases the online contacts offered are related to the treating clinic (c.f. www.varldguiden.se). Using the health portal patients require information seeking skills as well as knowledge of how to communicate in an online environment.

⁸ An earlier version of this web site is www.infomedica.se



Screenshot of a web site about Multiple Sclerosis produced by a patient in UK (www.mswebpals.org).

The second form of web page illustrated by the screenshot of Jooly's Joint represents Internet resources produced by private individuals. Here the user is offered a variety of facilities. The purpose is to serve as an additional information resource for patients with particular interests rather than a main starting point for Internet use and the offered facilities are mainly focused on the particular illness. For patients this particular form of Internet pages demands competencies to judge the relevans and accuracy of the information provided. In addition, to participate patients must be familiar with the use of different forms of interactive facilities.

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Screenshot of the U.S. National Institutes of Health (NIH) digital archive (www.pubmedcentral.nih.gov).

The final screenshot illustrates a type of Internet resources used by patients containing advanced medical information. It is a database providing free access to scientific abstracts and/or fulltext articles from various medical areas. To use this particular type of Internet page demands competencies such as information seeking skills, language skills as well as abilities to judge the relevance of the information found.

2.5 THE INTERNET IN THE PATIENT - HEALTHCARE RELATIONSHIP

To meet future challenges as earlier mentioned, there are great expectations on the development and use of information technology in general and on Internet in particular (Rice & Katz, 2001; Murero & Rice, 2006; Wilson, 2003; Wen & Tan, 2003). Making use of the Internet involves ideas to develop technical solutions contributing to an effective communication and resource employment in healthcare practice and to increase or maintain the level of service with present resources despite expectations of an increased patient stream. However, so far the Internet is an underused healthcare resource although emergent in several respects (Rice & Katz, 2001; Murero & Rice, 2006).

One emergent area concerns the health portals⁹ produced by the public healthcare mentioned earlier. These web sites provide medical information on numerous health conditions, practical information (like opening hours, telephone numbers, fees and so on), and information about patient rights. In addition, the pages provide information specifically directed towards children and there is information on health management issues (like healthy food, physical exercise, and risks of smoking and alcohol). Only to a limited extent, the portals offer contact with the treating clinic. Additionally, the health portals address the general public as well as patients of different kind. This means they are not designed specifically to meet the requirements of chronically ill patients.

Besides the health portals, the healthcare offers medical and practical information through web sites connected to particular hospitals or clinics. In addition, the County Councils provide general information about their different practices. A few of these online resources offer patients direct contact with their treating clinic for services like renewal of prescriptions, to book/cancel appointments, and obtain medical advice from healthcare professionals (not necessarily connected to the patients' treating clinic). The level of implementation of these services varies across the country.

However, in *treatment situations* and during chronically ill patients' *long time regular contacts*, the use of the Internet is still rare. More specifically, chronically ill patients' possibilities to make use of the Internet as a (local) resource for information and contact with their *treating* clinic and/or doctor are still limited. Future development of this use of the Internet in the patient-healthcare relationship is particularly important in this thesis.

Internationally and in Sweden there are ongoing projects aiming to further utilize the Internet in terms of an active and complementary healthcare resource (c.f. Carlbring & Andersson, 2006; Leimeister et al., 2004; Murero & Rice, 2006; Shaw et al., 2004). Besides the provision of additional medical information some examples involves online resources related to the particular treatment (like in some psychological treatments). Other examples offers e-mail contact with treating clinic/doctor and the possibility to interact with fellow patients online.

3. METHOD

This section describes the interpretive approach by which the work gradually developed. First however, I introduce my personal point of departure and the main features of the research process.

⁹ Examples of Swedish health portals produced by the public healthcare are: www.sjukvardsradgivningen.se, (former infomedica.se) and vardguiden.se.

3.1 THE RESEARCH PROCESS

The research process in this thesis probably set out more than twenty years ago. At this time, I worked as an assistant nurse in different clinics within the Swedish healthcare system. Even though my working life has taken new directions since then, my interest for healthcare related issues has never ceased. I was introduced to information technology through other employments but when I decided to deepen my studies in Informatics my area of interest was clear. The fact that I focus on the patients I consider a development of my field of interest in relation to my own developing Internet use and personal experiences of contacts with the healthcare.

This background together with other life experiences, are important parts of my research work. They constitute the filter through which I have developed the picture of patients' use of the Internet presented in this thesis. As I have applied a qualitative approach this circumstance is a central ingredient. The often disorganized set of qualitative data requires the researcher to search for patterns and connections. In this search process it *"is necessary to listen not only with the tidiest and most precise of one's cognitive abilities, but also with the whole of one's experiences and imagination"* (McCracken, 1988, p. 19). Naturally, this brings a personal picture of a certain phenomenon. However, it is my conviction that any other picture is difficult to provide since we all carry our own stories influencing and shaping the world we see and the way we observe it. To widen my understanding of the phenomenon, I have tried to be aware of my conceptions and as far as possible revalue my own assumptions (Klein & Myers, 1999).

Similarly, I view the statements of my interviewees as representations of their individual experiences and worlds. This reflects the social constructivist basis (Berger & Luckman, 1966) of this work and corresponds to ideas within the tradition of interpretive IS studies (c.f. Walsham, 1995; Klein & Myers, 1999). Further, this means my underlying philosophical stances can be traced to an ethnographical research tradition (Goffman, 1959, McCracken, 1988). Also, my care for the possibilities to provide a "thick description" (Walsham, 1995) of the phenomena signals this.

Following this, an exploratory and interpretive research approach guided me through the work in the sense that I have moved into the area carrying only the question of "What takes place?" My intention was to search for the activities that go on and let them guide my understanding of the phenomenon. A long the way this gave rise to more questions like "How?" and "Why?" More specifically, this means that initially I searched broadly for patients' activities on the Internet and subsequently focused on separate actions and explored the context and possible driving forces. In addition, this indicates my role as a researcher being that of the outside observer (Easterby-Smith et al., 1991). However, I do not consider this role as neutral since by entering the field, meeting patients and asking questions I

still have influenced the particular context and the messages I have received (Walsham, 1995).

With this approach outlined, the presented understanding of patients' use of the Internet is the result of an iterative process related to the hermeneutic circle (Gadamer, 1976; Klein & Myers, 1999). The researcher's movement between the whole and the parts characterizes this process. In this thesis work, the parts would typically be studies of patients' individual steps and activities on the Internet while the whole would refer to reflections on the meaning of these activities to patients as individuals, to the role as a patient, and to the societal level. Alternatively, the activities per se would constitute a whole while specific features of a particular activity represent the parts.

In the initial stages of this iterative process, my objective was to get an overview of patients' use of the Internet. To get this general view I choose the strategy to get in contact with a number of patient associations active on the Internet. Through representatives of the associations, I was provided these actors experiences and picture of patients' use of the Internet. This step was an important beginning as it was grounded on the contact with several thousand patients. However, the picture was also coloured by the associations' requirements and use of the Internet for organizational purposes. Therefore, to increase my possibilities for a patient perspective it became important to approach patients on the Internet individually.

During the next step in the research process, I therefore went searching the Internet for patient activities. The observations showed that patients are engaged in various forms of online discussions. For instance, open bulletin boards accessible at different forms of healthcare related web sites (provided by private as well as public actors). However, in my endeavour to get close to patients activities and to be able to give voice to them I concentrated my work on online groups started and managed by patients. My idea was to get a broad experience of this particular online phenomenon and therefore I chose to depart from online groups representing different chronic illnesses.

Later in the research process, I wanted to add to the picture the experiences from patients that were not necessarily participants in online groups. In addition, I also wanted to deepen the picture by providing an example from a group of patients suffering from the same diagnosis. At this particular moment in the thesis work, I was provided the opportunity to get in contact with a specific patient group namely prostate cancer patient.

Attempts to capture patients' specific use of information technology could of course be made in several ways. My choices are one example characterized by my movements from the general to the specific coloured by my ambition to provide a broad picture. The following subsections present my movements in detail.

3.1 RESEARCH CONTEXT

3.1.1 Patient associations

Traditionally patient associations are non-profit actors representing patients on the public arena providing its members with information and support. In Sweden, patient associations must be registered at the local tax office and apply certain administrative features and functions like statutes and a governing board where the members have individual task (Carlsson, 2005). The financial basis of the associations varies where some may receive funding (dependent on the number of members). The main income source is however, memberships fees and private donations (ibid.). Larger associations have central, regional as well as local organisations while smaller associations are mainly locally based. However, the increasing use of the Internet in the associations is changing this situation. By means of the Internet, smaller associations can reach larger groups of people in a simplified and less expensive way and they are less geographically bound. The home page acting as “the window” helps smaller associations make a substantial and solid impression. In addition, the Internet serves as a new channel for contact with members (or potential members) and supports the associations’ internal co-ordination work. Thus, generally the Internet contributes to make the physical, geographical, and financial organization of the associations less significant in order to connect with the members and society at large. The Internet sites of the associations typically contain information about the disease, patient rights, and news from healthcare and medical research as well as information about relevant healthcare policy issues. In addition, there is information about the association’s activities and developments as well as possibilities for contact. Also, interactive facilities for the members are common.

In this thesis, the following Swedish patient associations participated:

- The Swedish Association of Hard of Hearing People
- The Swedish Whiplash Association
- The Swedish Rheumatism Association
- The Swedish Parkinson Foundation
- The Swedish Diabetes association
- The Swedish Psoriasis association
- The Swedish Tourette association (later The National Association Attention)

3.1.2 Online self-help groups

A specific form of patient activity explored in this thesis is patients' online self-help groups¹⁰. In Sweden and in other Scandinavian countries these forms of groups are recent phenomena as opposed to the Anglo-American countries having a long self-help tradition (Karlsson, 2006; Kummervold et al., 2002). There seems to be no exact definition of the concept of self-help group and some of the confusion relates to linguistic and cultural differences (Karlsson, 2006). Therefore, the following aims to characterize online self-help groups in the context of this thesis.

Patients themselves start and manage these online groups. They are based in the particular needs related to facing a certain illness and there is no direct involvement of the healthcare. Mutual support to deal with their problems is central in the groups but no precondition as patients may find the support they look for by passive participation or so-called online "lurking" (Preece, et al., 2004). In addition, the self-help groups have no administrative or formal structure like patient associations.

Patients' online self-help groups may have different appearances on the Internet. The following gives a short description of the main characteristics of the participating groups in this thesis (a thorough presentation of the groups is available in paper 3 and 4):

Typically, the groups offer a set of web pages containing a variety of medical, practical, and social information related to a specific illness. In addition, the groups provide interactive facilities like discussion boards, e-mail lists, and chats. The knowledge and interests of the initiating patient (or group owner) influence the technical design as well as the structure of the social interaction. The groups are Internet based though in some cases the online group interaction may trigger off-line meetings as well.

3.1.3 Patients

The participating patients in this thesis suffer from chronic illness or injury (see section 2.1). All of them are Internet users although with varying qualifications. A few are educated in the field of information technology and work as IS professionals. On the other hand, some of the interviewees are more or less self-taught regarding their knowledge about Internet use. Some were even triggered to get a computer and an Internet connection as they became ill. Other interviewees work in (or are retired from) professions where they are familiar with Internet use from their daily working routines.

In the studies, I interviewed 18 patients (see Table 2). The age of the participants varied between 25-67 year and six of the interviewees were women.

¹⁰ In some of the earlier papers in the thesis I use the term 'patient online communities'. To emphasize the aspects of mutual support in the groups I later developed the use of 'online self-help groups'.

The male dominance among the participants relates to my choice to focus on a particular patient group with a common diagnosis. In the case of this thesis, this common diagnosis is prostate cancer. Section 3.3 further treats the selection of participating patients.

3.3 DATA COLLECTION

Table 2 below summarizes my research studies. From the table it appears the main research method employed is the semi-structured interview. As I performed the interviews in the same way across the separate studies, I therefore account for their performance collectively in section 3.3.1. The observations and the questionnaire are described in detail in connection to the presentation below of each study respectively (section 3.3.2).

Study	Method	Time of study
1) Patient associations	Interviews (7)	February – March 2000
2) Self-help groups	Observations (15)	January 2002
3) Self-help groups	Questionnaire (1)	February 2002
4) Self-help groups	Interviews (10)	March – May 2002
5) Prostate Cancer patients	Interviews (8)	November 2003- February 2004

Table 2. The performed research studies

3.3.1 The Interview performance

I performed the interviews as a conversation with the respondents. This means I used open-ended questions following a semi-structured approach with a few specified question areas. McCracken (1988) inspired my development of the interview procedure in the sense that I used “grand-tour questions” and “prompting strategies”. More particularly this means that after the introduction and biographical questions I started the interviews with a general grand-tour question about a specific question area. Listening to the answer, I then tried to capture key words, themes or particular events I then tried to make the respondent develop further. To accomplish this I used techniques (prompting strategies) such as questions for comparison, questions about specific examples, new elements or categories mentioned. To be able to focus on the interview performance and the respondent I tape-recorded the interviews with permission of the respondent. The interviews lasted for 40-75 minutes and later transcribed verbatim. Finally, the participants were guaranteed confidentiality and the names used in the presentation of the data are fictitious.

3.3.2 The research studies

Study 1: Patient associations (interviews)

The purpose of the study was to get a general introduction to patients as adopters and users of the Internet for medical information. Therefore, the point of departure was Internet use by patient associations and their contacts with patients. I applied this approach in order to analyse the online activities of large and varying patient groups. Using four lists on the Internet containing information about Swedish patient associations the selection was guided by the provision of interactive online facilities. I contacted seven associations for participation in the study. Each of the associations represents a specific group of patients with a certain diagnosis. An ambition to cover diagnoses related to different ages as well as associations of varying sizes further guided the selection. The seven (7) interviewees serve as chairs or official informers at the associations. In addition, they have personal experiences of the disease/injury and of being a patient using the Internet for medical information. The study comprised seven (7) interviews.

Study 2: Self-help groups (observations)

The study involved observations of Swedish online self-help groups. The idea was to examine groups initiated and managed by private individuals addressing a special illness or patient group. By using Internet search engines such as “AltaVista”, “Google” and “Yahoo” these criteria guided the selection of 15 self-help groups representing chronic health disorders such as multiple sclerosis, endometriosis, fibromyalgia, and whiplash. The lists of patients associations mentioned earlier provided examples of possible diagnoses. To find the particular online groups I then combined the diagnoses with phrases such as “my story” or “my illness” or “patient stories”. The selected self-help groups had been online between two and seven years. The observations resulted in an initial understanding of the technical and social structures and the performed practices within the groups.

Study 3: Self-help groups (questionnaire)

The second study consisted of an introductory questionnaire performed in four (of the 15) self-help groups with the purpose of highlighting patients' experiences and expectations of the use of online medical information and emphasizing their ideas of how to use the Internet in the relationship between patients and the healthcare. Two discussion boards and two e-mail lists comprise the self-help groups in the study. The questions asked were open and concerned areas of patterns of use and what the patients appreciate most about the online community and the use of Internet for medical information but also what they believe can be improved and further developed.

The questionnaire resulted in 39 answers being less than expected. The total answer rate I can only estimate since two of the participating groups were open

to all visitors of the web pages. The other two groups (the e-mail lists) had 205 members at the time of the questionnaire. However, even though the questionnaire was limited in several respects, the participating patients presented rich pictures of their experiences and ideas for the future. Among other things, their Internet experiences involved the use of various online medical resources, meeting healthcare professionals as an online-informed patient and online interaction with fellow patients. Their stories served as an important introduction to the area and guidance for my future work.

Study 4: Self-help groups (interviews)

To get closer to patients and their perspective on Internet use the study involved patients that share the experience of initiating patient managed self-help groups on the Internet. The idea was to capture “patients in action” on the Internet meaning that the interaction and communication activities performed were central. Therefore, the selection of patients as initiators and managers of self-help groups was guided by the interactive facilities provided and the “patient activity” that occurred in the self-help groups. In addition, to get a broad patient perspective the ambition was to let the selected patients represent several diseases and health conditions. From the 15 self-help groups earlier selected for observations (see study 1) 10 initiators agreed to participate.

Study 5: Prostate Cancer patients (interviews)

The study consisted of eight (8) interviews with patients suffering from prostate cancer (PC). The aim was to focus on patients with a shared diagnosis to provide a deeper example of the specifics of making use of the Internet when facing illness. In short, PC mostly strikes elderly men and more than two third are over 70 years old. This type of cancer is the most common cancer among men. In Sweden there are about 9,000 new cases each year (Swedish Cancer Society, 2006) and the American Cancer Society (2006) estimates that there will be about 240, 090 new cases of PC in the U.S. in the year 2006. The incidence of PC makes the patients an important group to follow also when it comes to Internet use and the specific requirements for online activities related to the diagnosis. Cooperating with the Department of Oncology at the Sahlgrenska University Hospital in Göteborg (Sweden), contacts were established with prostate cancer patients interested in participating in the study.

3.4 DATA ANALYSIS

With an interpretative approach (Klein & Myers, 1999; Walsham, 1995), my research in this thesis aims to capture patients’ use of the Internet as a social phenomenon. This means I aim for a kind of knowledge recognized by illumination and understanding rather than causes of behaviour expressed in statistical terminologies. An interpretative approach involves particular

challenges regarding the establishment of validity and reliability of the work as these concepts stem from the research recognized by positivist approaches (Silverman, 2005). Hammersly (1990) describes validity as *“the extent to which an account accurately represents the social phenomenon to which it refers”* (p. 57). To establish validity in my work I have taken a number of actions. First, I aimed for a detailed description of the research process, the research context, the process of selection, and the methods used in collecting my data. Second, I analyzed the data using an inductive process where I read and reread the material searching for patterns and features (Silverman, 1993). Initially this involved identification of general patterns and features running through the data. The following stages sifted out additional patterns and features on gradually more specific levels. In addition, this inductive process involved seeking for deviant cases. Further, the data analysis involved the seeking of patterns within each performed study as well as across the studies. In sum, this means my data analysis aimed for what Silverman (2005) denote a “comprehensive data treatment”.

In addition, the constructivist paradigm that characterizes this thesis brings a special meaning to issues of validity and reliability. The paradigm opens up for the possibility of multiple or diverse constructions of reality. An approach involving the use of several methods and information sources for data collection is therefore fruitful to enhance validity and reliability (Golafshani, 2003). As described earlier, the multiple method and data source approach has been part of my work as well. Additional efforts to improve the reliability of this work are my approach to provide the reader with excerpts from the empirical data (Silverman, 2005). This was accomplished mainly through quotes from the interviews. However, since the interviews were conducted in Swedish, the quotes presented have been translated. To ensure that the overall meaning of each statement is captured and to avoid translation bias, the extracts have been discussed and double-checked with research colleagues.

In addition, parallel to my search for patterns in the material I also explored relevant theoretical instruments further supporting my data analysis. As an example, the interviews with the initiators of self-help groups revealed patterns indicating that the initiation was connected to deep psychological needs to create meaning of the personal situation and experience of the illness. Here the ideas of coping contributed to my increased understanding of the underlying mechanisms influencing some patients to initiate self-help groups. At the same time, the theory guided my continuing search for additional signs of coping behaviour. Another example is the understanding of the information seeking process. In the material, I could initially observe the different ways patients pursue their online information seeking. However, theoretical concepts from Information Science supported my categorization and gradual understanding of them.

4. COPING

In my attempts to understand patients' use of the Internet, there was one particular aspect that increasingly demanded my attention. This was the fact that the use of the Internet for the studied patients seemed to relate to a *deeper personal process* of dealing with the illness and the changing situation at large. The extent and the energy that characterized their Internet use and frequent descriptions of the online activities as a form of "treatment" and part of their own "therapy" supported my understanding. The patients' personal and detailed stories of the role of Internet use under difficult circumstances demanding adjustment to a new and changed life situation further guided my interpretation.

The search for instruments to help me understand and explore the phenomena led me to the field of psychology and the ideas of *coping*. In this thesis coping serves the purpose to understand a phenomenon and to structure the empirical material. This contrasts approaches where theory supports problem definition, data collection and analysis (Silverman, 2005). Although coloured by my previous experiences (section 3) my ambition was to approach patients' use of the Internet in a flexible and open-minded way. This ambition motivates the use of theory in this thesis.

By the ideas from the field of coping research, I learned that facing chronic illness demands a personal way to physically and mentally deal with a new life situation (Krohne, 1996; Lazarus & Folkman, 1984; Maes et al., 1996). This involves a dynamic process bordered with individual strategies to make sense of issues that surround the particular situation. Inspired by the ideas of coping I was able to understand patients' use of the Internet not only as separate online activities to support disease management in a practical sense but also as a sophisticated instrument to satisfy fundamental human needs in stressful situations. In addition, I learned that the coping *activities* performed should be considered as interrelated with the *context* in which they take place (White, 1985; Folkman & Moskowitz, 2004; Maes et al., 1996). More specifically, the process of *mediation* between the activities and the context illustrate how they influence each other. Section 4.2 further discusses the relation between the concepts of context, activity and mediation.

These concepts form the point of departure for my understanding of patients' use of the Internet as complex and dynamic phenomenon. However, in order to account for some of the details of the Internet use and to be able to provide a comprehensive picture, I found it necessary to let other instruments (presented in detail in section 4.2) complement the theoretical basis of the thesis. Therefore, to capture the *patient context* insights from the research field of Information Science and the model of "Information Use Environment" (IUE) (Taylor, 1986; 1991) complement the coping ideas. Here, IUE brings the opportunity to capture the complexity of the patient context covering individual

aspects as well as features of the larger social environment. In addition, the same research field support my work in understanding *patients' online information seeking* as a particular form of coping. More specifically, to understand how patients make their way through the vast amount of online information I apply features of Wilson's (1997) "General model of information seeking behaviour". Further, to deepen the picture of *patients' online self-help groups* as a coping environment CMC (Computer Mediated Communication) studies and the model of the "Emergence of online community" (Baym, 1995; 1998) support my work. Baym's model facilitates an analysis of the building blocks forming the group environment.

Together with the ideas of coping that inspired my thinking these complementary theoretical instruments form a model supporting my presentation and understanding of patients' use of the Internet in terms of *coping online*. However, before I present the model in detail I would like to develop my thinking on the choice of coping as my theoretical departure.

In many ways, patients' use of the Internet concerns their efforts to understand and manage a new life situation. Besides the ideas of coping, other theoretical constructs could have served as means to capture the phenomenon. As the subject of the thesis relates to efforts to manage difficult situations and that it resides in the field of Information Systems research an apparent choice of analytical tool might have been Karl Weick's (1995) ideas of sensemaking. This viewpoint offers a process perspective and a set of useful concepts aiming to capture individuals' sensemaking actions as they move from a state of chaos to gradual understanding of the situation. In addition, there are previous experiences of applying sensemaking to situations of IT use (Henfridsson, 1999; Seligman, 2000).

However, even though there are voices stressing the behavioural dimensions of sensemaking (Magala, 1997; Weick et al., 2005) it is a perspective that resides in a tradition of organizational thinking. Coping, on the other hand, is embedded in studies of health and well-being as well as disease management. As one of the main ambitions of this thesis is to get close to a patient perspective, I therefore made the choice for coping as my main theoretical instrument as these ideas are based in traditions closer to my object of study. In addition, based in the psychological field coping adds a behavioural perspective to our overall understanding of IT use (Beaudry & Pinsonneault, 2005).

4.1 THE CONCEPT OF COPING

To provide an initial understanding of the concept of coping I use the words of White (1985) explaining when coping might be an appropriate concept to employ:

“[...]it is clear that we tend to speak about coping when we have in mind a fairly drastic change or problem that defies familiar ways of behaving, requires the production of new behaviour, and very likely gives rise to uncomfortable affects like anxiety, despair, guilt, shame or grief [...].” (p. 122)

Coping is thus about how we deal with the stress related to difficult and unusual life events. In addition, it is concerned with our responses, not only from a practical point of view, but from a physical, emotional, and psychological perspective as well (Snyder, 1999).

To understand the concept of coping it is important to get a historical view as well (Gullacksen, 1998). This supports the appreciation of the complexity of the concept involving additional aspects besides the actual activities to deal with difficult life situations.

The concept has developed along two major paths. The first concerns influences from psychoanalytical theory and the field of ego-psychology (Snyder, 1999). In this field defence mechanisms (Haan, 1977) constitute an important basis for the discussion on individuals' adaptation to difficult life events. The primary focus is on enduring “traits” or personality deciding the coping behaviour. This view relates to coping as a stable and an unchangeable way of dealing with difficulties regardless of the situation.

Cognitive psychology and the research on stress influenced the second path. Early research in this field concerned the human biochemical response scheme ('fight or flight' responses) when exposed to stress (Seyle, 1956). However, these ideas were abandoned by sociologist Richard S. Lazarus and colleagues who was first to move the focus towards *active appraisal processes* leaving behind earlier ideas of traits (Lazarus, 1966). Instead, Lazarus's ideas of coping involved a transactional model focusing on the interaction between the individual's cognitive appraisals and the environment. The well-cited definition of coping provided by Lazarus and Folkman (1984) describes coping 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 & Folkman, 1984, p. 141)

Contrasting the ideas of traits as automated ways of coping (Snyder, 1999) this conceptualization involves a *process-oriented* and *context dependent* view of coping affected by the development of the situation and the person's reappraisal. This refers to the following process: when exposed to stress an individual makes a first *primary appraisal* of the situation. If the situation is perceived a potential threat, a *secondary appraisal* is made when the person investigates the available resources to deal with the threat (or stressor). Following the efforts to cope with the situation is the stage of *re-appraisal*. The individual then evaluates the results

of the coping behaviour in order to decide whether a threat is still present and/or if alternative coping efforts are needed.

The responses of a woman just diagnosed with a particular form of cancer can serve as a clarifying (yet simplified) example of this process. Here the situation of being diagnosed with cancer represents the potential stressor. In the initial stage the woman makes a first assessment of the situation (primary appraisal) to decide the nature of the situation and if it involves a threat. As she finds the cancer diagnosis a threat, she makes a second assessment (secondary appraisal) where she decides what to do and what resources there are. This second appraisal is the basis for the coping strategies she chooses and the activities she performs. Later she evaluates the outcomes of her efforts in a stage of re-appraisal leading to either additional coping activities or decisions that the stressor is no longer present. Using Beresford's (1994) representation Figure 1 serves the purpose to illustrate this process further.

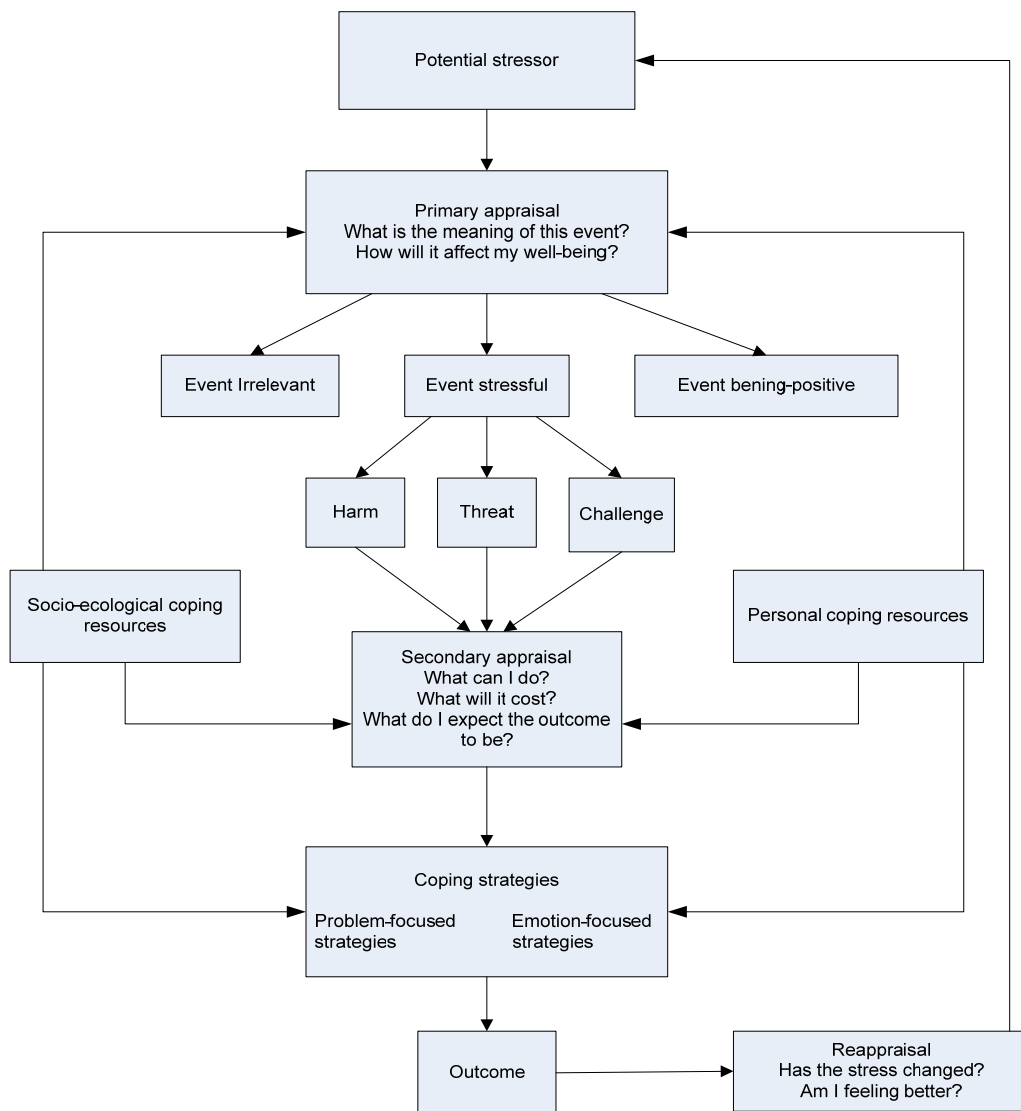


Figure 1. Beresford's (1994) process model of stress and coping.

Dealing with the stressful situations individuals combine coping strategies in performing different *coping activities*. Lazarus & Folkman (1984) identified two major functions of the coping strategies; *Emotion-focused coping*, referring to activities aiming to regulate the emotions and the perception of the situation; *Problem-focused coping*, directed towards the management of the problem and altering specific aspects of the environment that is causing the distress. Returning to our simple example with the cancer patient, emotion-focused coping might involve coping by searching for contacts with fellow patients for social support and human understanding. Alternatively, our patient might choose to deal with her emotions by denying or in other ways (like by using alcohol or drugs) try to escape the feelings involved. On the other hand, if she applies a problem-focused form of coping she might instead get involved in information seeking procedures in order to learn as much as possible about her diagnosis, available examinations and treatments. In addition, a problem-focused approach might involve the seeking of possible causes and explanations to the situation.

However, people rarely apply problem *or* emotion focused strategy. Rather they use different forms of strategies at different occasions as well as during coping with the same stressor. The woman with cancer might thus cope differently with her situation depending on the development of her illness and situation at large.

Further, this relates to the coping process as *context dependent* meaning coping should be viewed in relation to the demands of the particular situation (Folkman & Moskowitz, 2004; White, 1985). More specific, this includes both internal personal and psychological aspects as well as external features of the environment (Aldwin, 1994; Maes et al., 1996). For the cancer patient in the example this means her coping process is affected by factors such as age, sex, education, and naturally, type of cancer diagnosis. Other influencing factors involve her internal and external resources to deal with the situation, such as resources related to personality, support from family and friends, and financial basis.

However, context dependency also relates to the mutual influence or *mediation* between the context and the coping activities. This refers to the recognition of coping as part of social and cultural structures (Aldwin, 1994) affecting coping behaviour and equally being affected *by* the activities performed. This mirrors an idea of individuals as co-creators of their environment where “[...] *coping involves changing the environment as well as oneself*” (Lazarus & Folkman, 1984, p. 233).

4.2 MODEL OF COPING ONLINE

Inspired by the preceding ideas of coping I introduce a model of coping online aiming to support the understanding and description of patients' use of the Internet as an online phenomenon (see Figure 2).

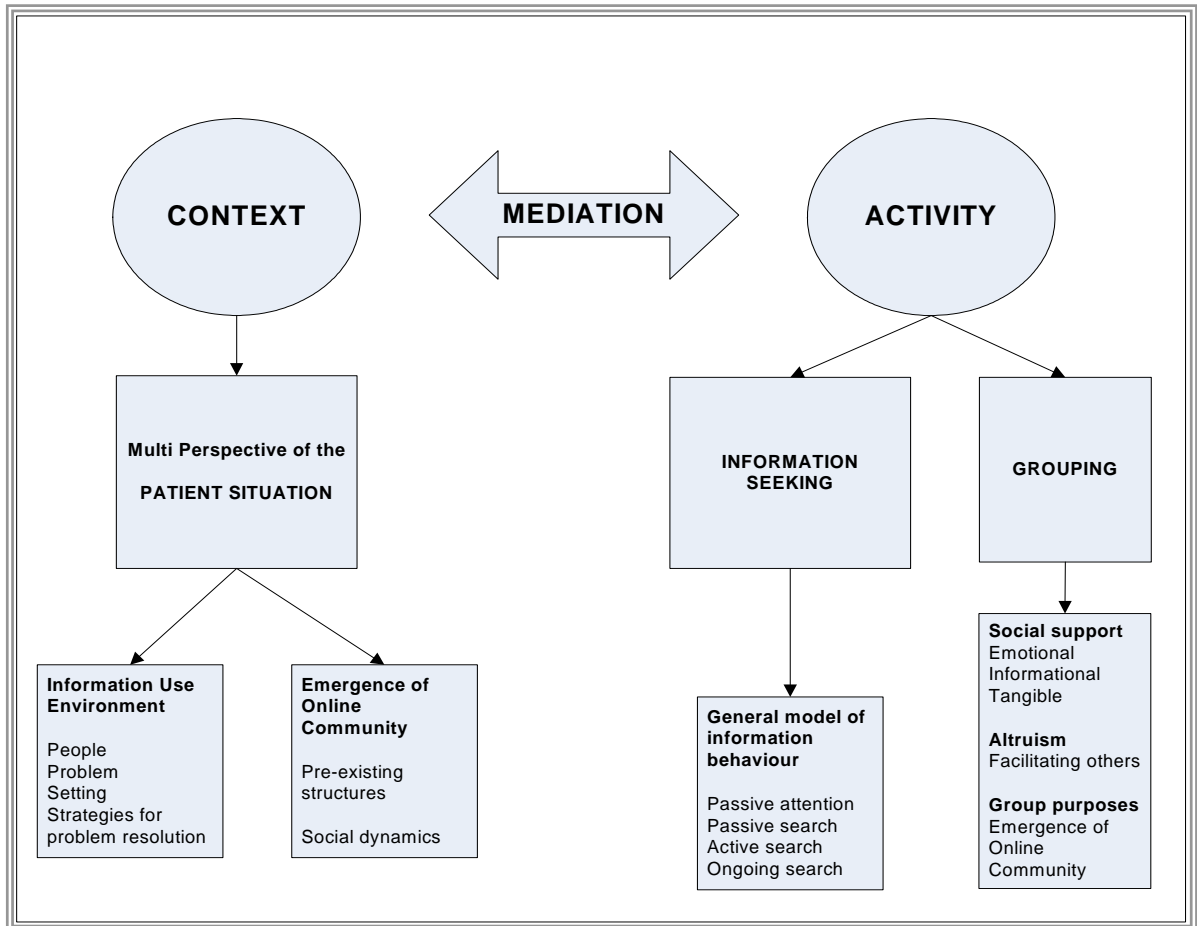


Figure 2. Model of patients' coping online

The model illustrates the elements of *context* and *activity* and their mutual influence (*mediation*). These notions depart from the coping literature above as well as from the gradual interpretation of the research material. Here, context relates to the emphasis in the coping literature about coping as contextual (Folkman & Moskowitz, 2004; Lazarus & Folkman, 1984; Monat & Lazarus, 1991; Snyder, 1999). The empirical material indicated this as well and I gradually noticed the differences between patients' personal, social and technical preconditions to go online and the influence this has on their way on the Internet and the online traces they leave behind. In a similar way, activity relates to the literature about the type of coping strategies an individual use in a

problem and/or emotion focused way (Lazarus & Folkman, 1984; Snyder, 1999). By means of these insights, I could gradually relate the observed online activities and the meaning the patients assigned to them with the ideas of particular coping behaviour. In addition, the notion of mediation grew from a similar process of literature influence and experiences of the empirical data. Here, I could see that the coping activities performed influenced future coping for the individual and in a wider perspective. Later I could relate this to discussions in the coping literature on coping as a process and that coping activities and the context in which they are performed influence each other (Aldwin, 1994; Maes et al., 1996).

The following section presents my *model of coping online* in detail. However, first I would like to make a few comments on how to read the model. Primarily, it is an instrument to structure my empirical data with the overall ambition to provide a broad picture of the features. In addition, it serves as an example of how we can understand patients' use of the Internet from the perspective of the individual. However, to use the model for a generalized view of online coping behaviour would demand additional studies and further refinements of the model. In addition, rather than illustrating the entire coping process - from appraisal to evaluation of coping outcome and re-appraisal (illustrated in Figure 1), the model illustrates *aspects* of coping that I observed during my studies. Finally, the large arrow of mediation illustrates that context and activity are interrelated. The smaller arrows point to components of the context and activity.

4.2.1 Context

Any effort to capture the patient context in relation to Internet use and coping online requires instruments sensitive enough to capture the patient situation using a multi perspective approach. This means it should mirror social, technical as well as personal and medical aspects of the patient situation. Even though the ideas of coping as outlined above emphasize the importance to consider coping as situated, coping can be criticized for bringing limited abilities to actually *capture and structure* a fine-grained picture of the particular coping context (Maes et al., 1996). Therefore, to complement the coping model in this respect I adopt Taylor's (1986; 1991) ideas of *Information Use Environment* (IUE) (presented in detail in paper 1).

IUE originate from the field of Information Science and work on information transfer. According to Taylor (1991), there are three main approaches to the study of information transfer. First, the technological approach focusing issues like structure and functions of information systems. Second, is the content-driven approach oriented towards classifications and ordering of knowledge and information. These two should be complemented and informed by a third approach: user and the uses of information and the

contexts in which the users are operating. These contexts Taylor denotes as “Information Use Environment” defined as:

“[...]the set of those elements that a) affect the flow and use of information messages into, within, and out of any definable entity; and b) determine the criteria by which the value of information messages will be judged.” (Taylor, 1986, p. 25)

Originally, IUE is used to “[...] structure what is known about information behaviour of defined groups of people [...]” (Hektor, 2001, p. 42). In the scope of this thesis, Taylor’s ideas serves the purpose to structure various factors of the patient context illuminating different preconditions for patients’ use of the Internet.

Taylor (1991) suggests four categories to describe the IUE: *people, problem, setting* and *problem resolution*. People, define the specific group and give the demographic and non-demographic components. For example, this category involves the role of age, sex and education when making use of the Internet. Also, it concerns personal attitude towards technology and/or preferences for technology use.

Problem refers to characteristic problems (such as a particular disease) and problem dimensions (like stages, phases or other disease characteristics). This category is thus concerned with issues of how the particular diagnosis might influence Internet use and the required scope of information.

Setting as the third factor involves the physical and social aspects of the users’ environment. This concerns the environmental factors on the individual level like personal knowledge and experiences of the illness as well as Internet use (like computer literacy, skills of online medical information seeking, knowledge of information assessment, and language skills). In addition, setting relates to values and attitudes of the environment like ideas of the democratisation of the healthcare and the changing patient role. Also, this aspect of setting involves perceptions’ about what constitutes appropriate coping strategies (Aldwin, 1994). Further, setting concerns issues of physical access (such as an Internet connection) as well as psychological access related to personal sources (like personal memory, friends, relatives, colleagues, and peers).

Finally, strategies for problem resolution concerns what constitute typical resolutions of problems for the set of people. This means to the particular ways patients deal with their situation also constitute a part of the context itself. Problem resolutions therefore constitute types of coping strategies usually applied by certain patients or patient groups. An example is the case of breast cancer patients. Here studies show this particular patient group often cope by participation in support groups or other environments allowing contact with others (Shaw et al., 2000; Maes et al., 1996).

Coping strategies involving efforts to connect with fellow patients online are specifically cared for in this thesis. In particular, those online spaces created and managed by patients themselves. Therefore, in terms of strategies for problem resolution as a part of the overall coping context, these spaces are here paid some extra attention.

Mainly, the groups are started because of someone facing illness or injury and cope with the situation, wholly or partly, by seeking contact with others online (paper 3). This background in personal coping processes influences the group environment contributing to a supportive and empathic context (Demiris, 2006; Johnson & Ambrose, 2006; Preece 1999). Attempting to further understand this particular strategy for problem resolution as a part of the overall coping context I apply Baym's (1995; 1998) model of "*The emergence of on-line community*" (see paper 4). The model is applied due to its abilities to provide a fine-grained picture of patients' online self-help groups as a particular aspect of the online coping context.

According to Baym (1995; 1998), the groups depart from the *pre-existing structures* that together with the *social dynamics* of the groups influences their emergence. The pre-existing structure involves a number of factors. First, the *external context* reflecting the online environment in which the communication is situated (such as the location of the immediate access to the technology) along with group relevant resources brought into the online community by its participants. In the case of patient self-help groups, this might involve medical experiences, knowledge of healthcare organization, social and technical knowledge of IT/Internet as well as professional and private life experiences at large.

Second, *temporal structure* involves the possibility to communicate synchronously or asynchronously, influencing the number of participants as well as the access to immediate feedback, and the possibility to write and rewrite messages. In addition, this concerns the maintenance of archives that afford the opportunity to visit past discussions. Third, *system infrastructures* concern the configuration and flexibility of the technology in addition with user-friendliness. Fourth, *group purposes* refer both to purposes basic for the existence of the community and to the purposes that emerge through interplay between the participants. For example, the basic purpose of an online group might be to inform others about a particular form of illness. As participants get in contact, the group develops a second purpose related to the idea of providing emotional support also.

Fifth, *participant characteristics* relate to different experiences and knowledge of the community theme. For patients this relates to the fact that some participants are newly diagnosed while others have long time experiences of living with a particular chronic illness. In addition, participant characteristics involve the diversity of social and geographical residence of the participants. Additional characteristics concern the size of the group and differences in general

experiences of information technology use, along with differences in age, sex, and education.

These factors of the *pre-existing structure* closely relates to the *social dynamics* of the group. According to Baym (1995; 1998), they are the result of the participants' appropriation and use of the resources and rules offered by the pre-existing structures. The social dynamics involves four categories. The first is the *forms of expression* in the group. This relates to the development of "group-specific vocabulary," "unique forms of jokes," and social cues like the use of nonverbal information such as smileys. Second, *identity* concerns how a name is created or how participants get "famous" in the group. For example, in some online groups participants must prove their knowledge and that they are experienced enough to guide others. Additionally, identity creation also concerns how the group deal with anonymity and made-up identities. Third, *relationships* relates to how group participants develop and maintain their relationships. Other aspects of relationships involve how online relationships go offline as well as the situations when the opposite occur. Finally, *behavioural norms* reflect what behaviour the group find socially accepted. Rules for "netiquette" often summarize this along with technical regulations that control the online communication.

Taken together the pre-existing structure and the social dynamics are considered a fruitful way to capture patients' online self-help groups as a coping context for the individual. In addition, these instruments describe how the groups are formed and the characteristics of the activities that takes place.

4.2.2 Activity

In this thesis, the ideas of coping mainly serve the purpose to understand patients' use of the Internet as opposed to map out various forms of coping behaviour performed in an Internet environment. The main online activities observed and analysed are patients' *information seeking* and their *grouping* activities.

Information seeking

Information seeking as a form of coping behaviour naturally can find expression in several ways. Regularly, it relates to a problem-focused way of dealing with illness aiming to control the threat, harm or challenge (e.g. illness). For instance, Sullivan & Reardon (1986) associates information seeking with a "fighting spirit" characterized by a highly optimistic attitude, a desire to know as much as possible and low levels of distress. Associated with this form of coping behaviour is Miller's (1987) categorization of "monitoring" referring to individuals who seek information about the threat they are experiencing. On the other hand, Miller recognized a variation in people's motivation for information seeking and termed the opposite behaviour (to avoid information about threats) as "blunting". In recent writings, Shiloh & Orgler-Shoob (2006) further stress the idea to consider information seeking coping in a wider context of individual differences. According to the authors information seeking is a coping style with

dual functions being problem focused *as well as* emotion focused. Thus, coping by engaging in information seeking procedures can be motivated by a need to deal with the illness per se as well as to regulate the emotions related to the facing of illness. For instance, information seeking might involve efforts to learn as much as possible about the disease but also to manage feelings like anxiety and fear as information seeking can give a sense of being in control of the situation (Johnson, 1997).

In this thesis, the duality of the coping function of information seeking is acknowledged. In addition, like coping at large information seeking should also be viewed as a complex interplay between individual preferences and the context as well as the relationship between them (Miller, 1987). This involves a process view of information seeking where the seeking efforts may evolve along with the progress of the illness (Johnson, 1997).

Capturing the search process is a complex undertaking calling for descriptions in terms of stages or phases and there are several models available that support our understanding of each of these as well as the process in general (c.f. Ellis, 1989; Kuhlthau, 1991; Napoli, 2001; Wilson, 1999). However, in my meetings with patients I found their information gatherings not only resulting from conscious choices to seek but also related to passive acquisitions. Therefore, I found it necessary to apply a model sensitive enough to cover additional aspects of the information seeking process as well. To meet this need, I adopted features of Wilson's (1997) "*General model of information behaviour*" (paper 2). This comprehensive model brings together ideas from different models, while also investigating a variety of disciplines beside information science (such as psychology, consumer behaviour, health communications studies and information systems design). In the section of the model focusing on information seeking behaviour, Wilson developed ideas of Ellis (1989) and Kuhlthau (1991) and added the passive modes of information seeking, sometimes termed "acquisition". Wilson's (1997) development was motivated by an ambition to illustrate the presence of additional search modes contrasting the previously strong focus on active modes. The search modes in Wilson's model are:

- *Passive attention*: where information acquisition may take place without intentional seeking (like reading newspapers, listening to the radio or watching television programs) still influencing online information seeking behaviour in a wider perspective.
- *Passive search*: signifies those occasions when one type of search results in the acquisition of information that happens to be relevant to the individual.
- *Active search*: where an individual actively seeks out information.
- *Ongoing search*: where active searching has already established the basic framework of knowledge, ideas, beliefs or values, but where occasional continuing search is carried out to update or expand one's framework.

In the thesis, these forms of information seeking were applied to capture and illustrate different forms of information seeking among the patients in the studies (paper 2).

Grouping

In the model of coping online grouping refers to patients' online meetings and interactions with one another focusing on patient managed self-help groups on the Internet. This form of online interaction usually refers to activities aiming at emotional support, human understanding and recognition of the personal illness experience (Gullacksen, 1998; Lazarus & Folkman, 1984; Wright & Bell, 2003).

Even though self-help groups offer various activities, the general concept of *Social support* usually describes this form of coping activity. Taking a closer look at the nature of social support as a specific form of coping activity it is important to keep in mind the diversity of the concept where researchers have identified various forms of social support (Lazarus & Folkman, 1984). For instance, Kahn (1979) separate between emotional support (referring to feelings and affirmations) and tangible support (like material assistance). Based on the work by Cowen (1982) and Caplan (1974) Milne et al. (2004) outline four forms of social support: informative (guidance), emotional (personal attachment, acceptance), practical support (practical assistance), and social companionship (social belonging and recognition). However, to guide my understanding of social support when coping online I use the forms of social support provided by Schaefer et al. (1981). This classification combines yet simplifies the previous descriptions and easily corresponds with my empirical material. The authors include three types of support: *informational* support (like providing information or advice and feedback), *tangible* support (involving direct forms of aid), and *emotional* support (including attachment and reassurance).

Broadening the perspective of social support is relevant to increase our understanding of patients coping online. It clarifies that social support involves practical and concrete aspects besides the social dimensions. Further, the seeking of various forms of social support indicates this form of coping as an emotion-focused as well as a problem-focused form of coping. Additionally, to clarify the diversity of social support contributes to an increased understanding of patients' preferences and what they actually do as well as the direction of their activities.

Closely related to social support is the strategy to cope by *facilitating others*. As a strategy for coping Vaillant (1977) discuss this in terms of altruism, which he describes as "*getting pleasure from giving to others what you yourself would like to receive*" (p. 110). Further, Vaillant's ideas of altruism origin from ego-psychology and is a part of his hierarchical model of defence mechanisms. Using defence mechanisms refers to individual efforts to deal with stressful situations and life adjustments as a part of personal continual growth. Vaillant models defence mechanisms in higher or mature levels of defence believed to be more effective than lower forms.

Altruism is found among the mature forms whereas repression, acting out and denial are considered as lower levels of defence.

Thus, altruistic behaviour is related to coping by seeking different forms of social support but with a specific focus on *providing* help. That is, this form of coping involves efforts to help oneself by helping others. Studies have found that the facilitator experiences improved health and benefits in quality of life (Schwartz & Sendor, 1999). However, studies found that providers are more helped than individuals receiving support (Brown et al., 2003; Schwartz & Sendor, 1999). Nevertheless, the beneficial outcomes of an altruistic behaviour is valid only as long as the provider is not overwhelmed with helping tasks and others demands which might cause negative health related outcomes instead (Post, 2005).

Nevertheless, Schwartz et al. (2003) argue that altruistic behaviour is important to recognize as a coping strategy to deal with stressful situations since “*altruism can regulate people’s perceptions of those internal and external realities they are powerless to change, and empower them to effect meaningful change.*” (p. 778). By considering this as a coping strategy in its own right, we are able to emphasize its importance in relation to other coping strategies and to understand its role in patients’ use of the Internet.

In addition, as a coping activity grouping may involve other activities as well. A fruitful way is therefore to capture online self-help groups as a phenomenon by means of their purposes. According to Baym’s (1995; 1998) model of the emergence of on-line community, the groups can adopt several purposes though they have a basic purpose from which the group departs. Other purposes then evolve as the group develops. For example, a self-help group starts with the basic purpose to serve as a space for additional information for patients suffering from a particular illness. Interactive facilities for discussions about the information are provided. As the group develops, the participants get to know each other and along the way a second purpose arise emphasising the group as an online arena for social contacts as well.

4.2.3 Mediation

There is a mutual influence between the coping context and the coping activities (Aldwin, 1994; Lazarus & Folkman, 1984; White, 1985). In the model of coping online (Figure 2) *mediation* illustrates this.

On the individual level, this concerns the role of personal preconditions and preferences to the choice of coping activity (Maes et al., 1996). Also, it concerns the effect of the particular coping activity on the personal context. For instance, a person facing illness makes the choice of problem-focused coping by searching for information about the particular diagnosis. The choice of this strategy is influenced by the context involving factors like diagnosis, age, sex, knowledge of information seeking procedures. Initially, the person might be an inexperienced information seeker but a long the way she develops her knowledge about the

disease as well as her information seeking skills. These experiences contribute to the development of the personal context influencing future coping activities.

Monnier & Hobfoll (1997) emphasize the relationship between context and activity on a social level in terms of communal coping. This refers to the consequences of individual coping in relation to social relationships and future coping efforts.

For example, the choice of strategy might affect people close to the coping person (like family, friends, and colleagues) as well as members of the social network in a wider perspective. Coping by denying or escaping problems by using alcohol or drugs is likely to cause a lot of strain on the relationships. Additional example is when the coping person turns to others than the circle of family and friends for support and human understanding. This might cause relatives to feel left out or unable to reach the coping person. On the other hand, such coping strategy can be a relief for relatives as they might be unable to support the person any further.

In addition, the process of mediation may also have implications on a larger sociocultural level (Aldwin, 1994). That is, aspects of the societal context influence the persons' decisions. For instance, when coping with illness this might concern demands to act the informed patient or to participate in health decisions as well as media exposure of Internet as a useful source of medical information. Affected by such societal aspects of the context the activities to cope in a certain way then contributes to the creation of awareness and development of new coping resources (Aldwin, 1994, p. 273).

Further stressing the societal level and wider perspective of mediation Lazarus & Folkman (1984) state there are political implications involved related to "*people as shapers and people as shaped*" (p. 234). The authors conclude that when we consider the mutual influence between context and activity there is a risk of ending up in a polarizing discussion where less successful coping outcomes are blamed on either the individual, coping in a wrong way or the society being unable to provide for individuals' needs.

In sum, mediation refers to a process of mutual influence, on the individual as well as larger social and societal level. In this thesis, I therefore consider mediation a carrier of contextual characteristics as well as outcomes of coping activities. Folkman & Moskowitz (2004) further describe the relationship between coping and the surrounding social structure as:

"Coping is not a stand-alone phenomenon. It is embedded in a complex, dynamic process that involves the person, the environment, and the relationship between them" (Folkman & Moskowitz, 2004, p. 748).

5. RESEARCH CONTRIBUTIONS

This section presents the results and contributions of my research starting with a summary of the papers. This is followed by a revisit to the model of coping online. Together the summary and the model form the basis of the analysis of the critical issues of patients' use of the Internet presented in the subsections thereafter. Aiming to learn from patients and their online activities the final section contains my understanding of how their use of the Internet might contribute to the advancement of Internet use in the patient–healthcare relationship. The subsections discuss implications of patients' coping online for the development of Internet use as well as for healthcare practice.

5.1 THE PAPERS

1. Josefsson, U. (2006a). Exploring E-patients' heterogeneity: Towards personalized E-health applications. In *proceedings of the 14th European Conference on Information Systems*, 12-14 June, 2006, Göteborg, Sweden.

The paper brings together the results from 25 interviews with patients and representatives of patient associations (study 1, 4, and 5 in section 3.3). Taking a patient perspective the purpose of the paper is to contribute to the emergence of online support for patients' disease management and communication with healthcare. By means of theoretical insights from Information Science and the ideas of Information Use Environment (Taylor, 1986; 1991), four components (people, problem, setting and strategies for problem resolution) serve as instruments to illustrate patients' heterogeneity. The results draw a complex and dynamic picture of patients' coping context with implications for the development of online technology use in the patient–healthcare relationship. The paper contributes with an introductory exploration of chronically ill patients' various preconditions as they enter the Internet to cope with their illness. It highlights the importance of flexible technical solutions considering the type of diagnosis and related specifics along with patient demographics as well as physical and social abilities for system use. Additionally, this includes a further acknowledgement of patients' various forms of coping strategies when dealing with illness.

2. Josefsson, U. (2006b). Patients' Online Information Seeking Behavior, In M. Murero, & R. E. Rice (Eds.) *The Internet and Healthcare: Theory, Research and Practice*, Mahwah, NJ: Lawrence Erlbaum Associates.

Using a qualitative approach departing from 18 in-depth interviews (study 4 and 5, section 3.3) with Swedish patients, the paper explores their information seeking on the Internet. The purpose is to capture characteristics of patients' search patterns

and, in a wider perspective, support the design of emergent forms of Internet-based healthcare resources. Informed by ideas from Information Science the presentation of the empirical data is structured around features in Wilson's (1997) General model of information behaviour (passive acquisition, passive search, active search, and ongoing search). In conclusion, this paper illustrates patients' different ways of seeking online information. The research findings discussed here give voice to patients' experiences and deriving from the empirical data the analysis focus on three themes related to consequences of the observed search behaviour: accessing online medical information, social support, and issues of information accuracy and applicability. In order to provide a nuanced picture, the findings further suggest that the search mode applied and the amount and type of information obtained should be viewed against the background of balancing factors. Stemming from the participants' experiences, the balancing factors considered here are related to patients' coping strategies, resource requirements, and online information seeking assistance available.

3. Josefsson, U. (forthcoming). Patients initiating self-help groups on the Internet: A coping perspective. *Submitted to the European Journal of Information Systems.*

The purpose of this paper is to increase our understanding of the driving forces of Internet use in private life. Drawing on ideas from coping theory this paper addresses patients' *initiation* of online self-help groups in Sweden. Based on observations and semi-structured interviews (study 2 and 4 in section 3.3) the paper provides a behavioural perspective on the initiation of the groups adding to previous focus on technical and social group structure as well as issues of participation. The paper identifies three main coping strategies involved in the process of initiating the self-help groups: information seeking, social support and facilitating others. These strategies involve management of external and internal problems related to facing illness. The paper concludes that a coping perspective indicates that the self-help groups *depart* from personal coping processes rather than group related interests. This means that a self-help group is the result from individual coping strategies performed in the context of that particular individual and that the online self-help group then serves the purpose to support further coping efforts of the initiator. This further relates to the ideas of coping as context dependent and involved in a process of mutual influence between the coping context and the activities performed.

4. Josefsson, U. (2005). Coping with Illness Online: The Case of Patients' Online Communities, *The Information Society*, Vol. 21, No. 2, pp. 143-153.

This paper is based on study 2, 3, and 4 (in section 3.3). The paper identifies and analyzes the characteristics of patients' online self-help groups¹¹ in Sweden using Baym's (1995, 1998) model of the Emergence of online community. Acknowledging the debate about quality of health information online and the potential risks of medical information on the Internet, the paper argues that a deeper understanding of the dynamics of patients' online self-help groups, which offer unique aides for the coping process of chronically ill patients, can contribute to the design of the emergent forms of Internet-based healthcare resources. The main purpose of the article is to increase our understanding of the specifics of the self-help groups as a unique type of online group. By applying the model, the paper presents a fine-grained picture, covering both the contextual structures and the community culture. Further, the model contributes by highlighting important features of the self-help groups central to patients' coping processes. First, the online groups provide patients with specific medical information related to their illness, involving both medical facts and human understanding. Second, they involve spaces for social support, providing the possibility to receive support as well as to help others. Third, the self-help groups represent spaces for health education, with implications on the individual and societal level. Allowing different learning styles such as active participation as well as lurking, the self-help groups support individual needs for the learning process about a disease. These features are believed to contribute as guidelines for design of the emergent Internet-based communication between patients and healthcare providers.

5. Josefsson, U. & Ranerup, A. (2003). Consumerism revisited: The emergent roles of new electronic intermediaries between citizens and the public sector. *Information Polity*, Vol. 8 No.3-4, pp. 167-180.

The purpose of this paper is to problematize the capacities to act that citizens are provided with by means of new types of electronic intermediaries (such as patients' online self-help groups) between themselves and the public services. By observing the web pages of self-help groups and interviewing the initiators of the groups (study 2 and 4 in section 3.3) the paper identifies and analyses four types of capacities to act (to learn, to inform, to provide social support and to influence public opinion). Analyzed against the background of the marketisation and democratization reforms affecting the administration and production of public services the identified capacities to act is characterised as means for citizens to use and produce information, to develop specific and general knowledge, as well as to act on an individual and a collective basis. This implies that the electronic intermediaries generate capacities to act that enable citizens to put new and

¹¹ In this paper patients' self-help groups are termed Patients' Online Communities (POC).

additional demands on the public service provided not only from a personal point of view but also from a more general and collectivistic. In the paper, it is concluded that the intermediaries are sophisticated instruments in a learning process that support the citizens' development into active consumers of public services.

5.2 THE MODEL OF COPING ONLINE REVISITED

Inspired by the ideas of human coping behaviour and complemented with other theoretical constructs, I developed a model of patients' coping online. The model is an important contribution of the thesis and it serves as means to build the analysis presented in the following. Therefore, I present the model once more (Figure 3) together with a summary of its components.

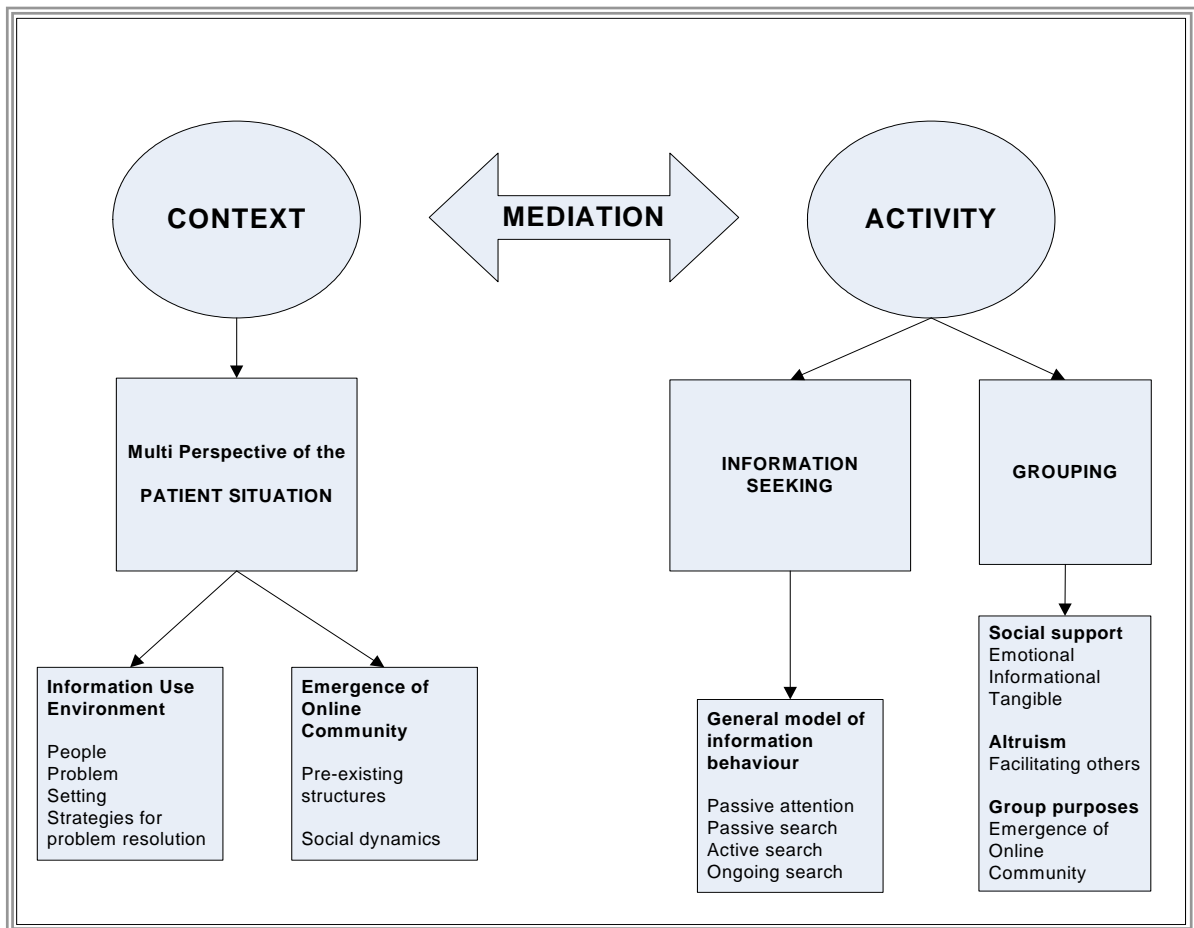


Figure 3. Model of patients' coping online

Coping online is related to the particular patient context. To capture the complexity of the context I apply the ideas of Information Use Environment

(IUE): people, problem, setting, and strategies for problem resolution (Taylor, 1991). These concepts form a basis to understand the patient situation from a multi perspective point of view as she makes use of the Internet. In addition, aiming for a patient perspective the online self-help groups formed by patients have a special place in this thesis. They contribute with a particular aspect of the coping online context. The Emergence of Online Community model (Baym, 1995; 1998) illustrates this adding a framework for describing the pre-existing structure and social dynamics of the groups.

The model of coping online includes two main coping activities that appeared in the studies. The first concerns information seeking online illustrated by the use of features of the General model of information behaviour (Wilson, 1997). Using the concepts of passive attention, passive search, active search and ongoing search, the model supports the capturing of patients different modes of information seeking.

The second form of coping activity is termed grouping. This involves patients seeking for contact with others in an online environment usually referred to as seeking of social support. This is a diverse concept here illustrated by tangible, informational, and emotional forms of social support. The second form of grouping in the coping model relates to activities where patients altruistically facilitate each other (Vaillant, 1977). As grouping may refer to other activities as well, it is fruitful to capture these by means of group purposes as referred to in the Emergence of Community model (Baym, 1995; 1998).

The coping context and the activities performed can be considered separately only for analytical purposes. In the model, the concept of mediation describes their relationship. It illustrates a mutual influence between the concepts where the coping context affects the coping activities. This further influences the context and future coping activities (Aldwin, 1994).

5.3 CRITICAL ISSUES OF PATIENTS' USE OF THE INTERNET

In the model of coping online the concepts of *Context*, *Activity*, and *Mediation* constitute the critical issues that will guide the analysis of the research results and contributions in the following. However, my journey through the landscape of patients' online activities departs from the individual use but reaches towards collective efforts as well. Therefore, in an attempt to structure the complexity of patients' use of the Internet, aspects of *Group* and *Society* dimensions will accompany the *Individual* view. These levels depart from the empirical material where group activities and the relationship with healthcare practice and public society at large, influenced patients' use of the Internet. In addition, the use of these dimensions is inspired by related research (see section 1.1). Also, the dimensions make an intuitive way to consider the phenomenon with the ambition to provide a comprehensive picture.

Further, it should be added that due to the scope of my studies, the group dimension mainly refers to the online self-help groups initiated and managed by patients themselves and to a less extent the activities in patient associations. The dimension of society refers to issues of the healthcare organization as a public sector entity associated with the Swedish government.

The coping online model captures the phenomenon mainly from the individual and group dimension. These dimensions are interrelated and support the overall patient perspective of the thesis. However, with the ambition to provide a comprehensive picture the level of society deserve attention as well. In the analysis, this dimension is touched upon to illustrate coping online in a larger social context. However, on the society level the model of coping online brings limited guidance to understand the critical issues of the phenomenon. In this respect, the model serves as an analytical tool in terms that are more general.

The following section outlines my interpretation of the patients' use of the Internet. To support my presentation, table 3 below illustrates the critical issues and dimensions of analysis. The key phrases in the table are given in italics in the sections that follows.

Critical issues Dimensions of analysis	Context	Activity	Mediation
Individual	<ul style="list-style-type: none"> * Diagnosis and related characteristics * Demographics * Preferences for technology use * Access to technology and information * Strategies for problem resolution 	<ul style="list-style-type: none"> * Information seeking: active and passive forms * Grouping: Social support: informational, tangible, emotional * Facilitating others 	<ul style="list-style-type: none"> * Supports personal knowledge development * Requires patients to develop strategies to manage situations of information overload * Facilitating others mutually influences individuals' coping context * Patients take on new or additional coping strategies
Group	<ul style="list-style-type: none"> * Based in individual coping strategies * Different purposes * Supportive, Emphatic, and Informative * The initiator influences technical and social structure * Rules of netiquette important 	<ul style="list-style-type: none"> * Inform * Learn * Social support * Influence public opinion 	<ul style="list-style-type: none"> * Contribute to the emergence of new forms of coping resources online * Supports the ongoing development of the self-help groups * Complementary healthcare information resources
Society	<ul style="list-style-type: none"> * Democratization of public sector services * Changing view of the patient * Widespread use of the Internet * Limited Internet use by healthcare professionals * Vast amount of medical information online * Digital/medical divide 	<ul style="list-style-type: none"> * Contribute to the emergence of the patient role * Challenge the medical expertise * Influence the public opinion * Act as producers and consumers of medical information * Take on a technological lead in relation to healthcare practice * Highlights issues of the digital /medical divide 	<ul style="list-style-type: none"> * The development of the patient role * Increases the availability of detailed and specific medical information * Forming the Internet as a coping arena * Reinforcing the situation of users non- users situation

Table 3. Summary of the patients' use of the Internet with critical issues and dimensions of analysis.

5.3.1 Context

Context: Individual

Patients' use of the Internet is highly situated suggesting the specific coping context should form the basis for an understanding of the phenomenon. Several factors influence the character of Internet use when facing illness. Those factors

that appeared clearly in the empirical data I structure in terms of the patients' Information Use Environment (IUE) (Taylor, 1986; 1991) (paper 1). This involves the concepts of people, problem, setting, and strategies for problem resolution. However, regarding patients the most intuitive way to present such structure is to depart from the problem (and problem dimensions). The particular *diagnosis and related characteristics* illustrate this, involving medical, psychological, and social dimensions influencing Internet use. This concerns the seriousness of the disease, longevity, issues of stigma, disease development, and forms of examinations and treatments together with their (side) effects. Thus, the results shows patients' problems and problem dimensions are complex generating various needs of medical information and psychosocial support both on the level of detail and regarding development over time (paper 1 and 2).

Beside the particular problem, patients as a "special interest group" (Taylor, 1991) constitute an additional important aspect of the patient context. This refers to Taylor's (ibid.) category of people describing the owners of the IUE. This involves the role of patient *demographics* influencing Internet use. This means aspects like age, sex, and education, are significant to Internet use as well as to the understanding of patients' different content requirements (paper 1).

In addition, this thesis indicates that there are non-demographic characteristics further shaping patients as a set of people (paper 1 and 2). This involves variations in the *preferences for technology use*. The patients in the studies are all Internet users although they express differences of attitudes towards using the technology for health related purposes. The research shows patients on a scale where some are very positive and enthusiastic towards the use of the Internet and describe their online activities in terms of their "life-line". On the other end of the scale, there are patients using the Internet in a limited way. Although they are familiar with Internet use and find it useful to some extent, they prefer personal contacts and face-to-face meetings with healthcare professionals.

Further, issues of the setting shape the patient context. This refers to physical and social aspects of the *access to technology and information*. In the studies, the patients had physical access to the Internet in their homes. However, they varied concerning their knowledge on how to use it and how to make their way on the Internet and assess the information found. Regarding the social aspects of setting the patients also had different ideas of and possibilities for complementary personal dialogues (with fellow sufferers, friends, relatives, and so on).

Finally, patients' strategies for problem resolution contribute to the picture of their IUE. The research results shows that some patients prefer active *strategies for problem resolution* like extensive information seeking, engagement in online discussions or activities to start online self-help groups (paper 2, 3 and 4). Others prefer more awaiting strategies such as seeking information in line with the disease development or to visit recommended web sites only (paper 2). There are similar patterns regarding social interaction online as a form of problem

resolution where some patients are active participants helping and supporting fellow patients. For others, the possibility to remain anonymous is important and there are patients that prefer not to reveal their presence at all.

Context: Group

At first glance, patients' online self-help groups are phenomena grown from the general diffusion and adoption of the Internet use in people's private life. Using the terminology of the model of Emergence of Online Community (Baym, 1995; 1998), many of the pre-existing structures of this form of online group are similar to other Internet groups. For example, the participants meet across geographical, social, and cultural borders. There is a lot of factual information about the particular group issue and there are interactive facilities to get in contact with others. The technical features (like discussion boards and e-mail lists) and the social and spatial issues are similar. In addition, like other online groups started and managed by individuals, the initiators of the self-help groups have varying technical, financial, and time resources to develop the groups, which influence system infrastructure (like system configuration and user friendliness). However, taking a closer look, the uniqueness of the self-help groups is found in the meaning assigned to this particular technology use by the group participants (paper 4). For instance, regarding interactivity, temporal structure and the possibilities to communicate asynchronously (using discussion boards, e-mail lists) and synchronously (by chats) serve a specific purpose in the self-help groups as patients coping with illness often experience a need to be able to get in contact with others for support and human understanding on a 24/7 basis.

In addition, there are features of the external context of the online self-help groups making them unique. For instance, they are based in conditions and events not controlled by the individual but with major impact on the life situation. Thus, the particular issues of the groups relate to something the participants have been stricken by rather than taken an interest in, on a free basis. The results of this thesis indicate these groups are *based in individual coping strategies* to manage the difficulties (paper 3). This implies a deeper psychological reason for the existence of the groups making them different from other online groupings (paper 3 and 4).

Further exploring the driving forces as a part of the external context, the work on the patient self-help groups (paper 3 and 4) indicate some common characteristics of the group initiators. First, they seem to employ a "fighting spirit" (Sullivan & Reardon, 1986) involving coping efforts of extensive information seeking or "monitoring" (Miller, 1987). Their efforts result in web pages containing large amounts of medical facts as well as information about how to manage everyday life living with illness. In addition, the information available is formed along with the participants. Through online discussions and illness stories, the patients create a sum of experiences. Viewed as a social practice this constitutes a group relevant resource brought into the online group by its participants (Baym, 1998). With different participant characteristics (from around

the country or the world, with different life experiences, long time sufferers, newly diagnosed, and so on) the group interactions shape and develop the collected experiences. In this development, an interpretive practice supplements the informative practices (Hardey, 2001) where patients draw upon their own and others' experiences of the disease to support each other to interpret information from doctors and other health care professionals (paper 4).

Online self-help groups have *different purposes*. The particular group purposes are a part of the overall coping context since they indicate the direction of the activities in the group. The performed studies (paper 4 and 5) identify four specific purposes: to provide social support, to inform, to learn, and to influence the public opinion (further described in section 5.3.2).

Extending the picture of the self-help groups, as parts of the online coping context, the social dynamics are important as well. They are the results of the participants' appropriation and use of the resources and rules offered by the pre-existing structures (Baym, 1995; 1998). In several ways, the results of the research work (paper 3, 4 and 5) picture the groups as a *supportive* environment characterized by an ambition to create a sense of belonging. With forms of expression characterised by a mixture of everyday and medical vocabulary sometimes together with a lot of humour, these groups are *empathic* and *informative* arenas for patient meetings. Despite the supportive context the participant identity are generally oriented towards anonymity. In the groups, there is a common understanding that anonymity is important due to privacy in general or issues of stigma related to the particular medical diagnosis (paper 4).

In addition, the *initiator influences technical and social structure* of the self-help group (paper 4). Personal choices related to procedures for memberships and moderations of discussions affect the development of identities and relationships. For example, applying formal registration or keeping the group open for any participant influence who will actually participate. In addition, some initiators start "off-topic lists" to support all patient interaction while others prefer to moderate and control the discussions. Further, paper 4 illustrates an additional aspect of the relationships in the self-help groups referring to the personal contact between the initiator and the participants. This concerns the sometimes heavy burden the initiator takes on, trying to support, comfort, help, and "push" others. In these contacts, they deal with worried relatives and distressed fellow patients, sometimes feeling badly treated or neglected by doctors and healthcare.

Finally, the supportive and empathic context of the self-help groups contributes to an emphasis on the behavioural norms of the groups. Many sensitive issues are discussed making appropriate behaviour and *rules of "the netiquette" important* (paper 4).

Context: Society

Several ongoing social processes describes patients' coping context on the level of society. For instance, the findings highlight that the coping context is coloured by the general process of *democratization of the public sector services* in the western world (paper 5). That is, the context for coping online is shaped by values and attitudes related to the idea of citizens as customers with increased participation and freedom of choice (Saltman, 1994). This development is ongoing in areas such as education, social services, and healthcare and is characterized by a competitive environment where institutions are competing for customers (Bellamy & Taylor, 1998; LeGrand & Bartlett, 1993). Regarding public healthcare in Sweden there are increased possibilities for patients to make choices of available services (Saltman, 1994) although there are some differences between County Councils in the degree of patients' choice of physician or hospital.

The coping context on a societal level thus involves a *changing view of the patient* (see section 2.2). Paper 2, 3, and 4 exemplifies how patients by means of the Internet act as the active and informed partaker characterizing the "new" patient as opposed to the former passive receiver of care. This however, involves not only the possibility to make choices regarding healthcare providers but also an expectation to participate in the making of healthcare decisions regarding examinations and treatments (paper 5).

Further, the society context is affected by changing possibilities of information access. The development of the patient role converges with the general diffusion of information technology use in everyday life. This refers to the *widespread use of the Internet* in people's everyday life. The results of the thesis reflect this development as the participants had Internet connections in their homes and at their work places as well.

However, in general healthcare professionals are recognized as slow adopters of new technologies and have tended to lag behind patients in the use of the Internet (Johnson & Ambrose, 2006; Morahan-Martin, 2004; Murero & Rice, 2006). *Limited Internet use by healthcare professionals* contributes to the picture of patients' performing their Internet activities with practically no professional guidance (paper 1, 2 and 5). The results of the research thus indicate that in order to meet the demands of the new patient role patients are thrown upon their own resources to get informed and to make sense of medical information online. The fact that the Internet contains *vast amount of medical information* put additional demands on patients to assess the information found (paper 2). This makes a potential risk for patients to become misinformed.

In addition, the results in paper 1 and 2 illuminate that coping online demands certain competencies and resources further shaping the coping context. This relates to patients different preconditions to access the required technology. This is captured in terms of the *digital divide* influencing the society context of patients' coping online. With a wide understanding of digital divide involving inequalities of all necessary resources needed to use the Internet for medical information (like

technical equipment, computer and Internet literacy, language skills, social contacts, and so on) the research results of this thesis emphasize the risk of a digital divide leading to a *medical divide* (paper 1, 2 and 5). This involves a situation where some individuals strong on resources get access to healthcare on different conditions than others.

5.3.2 Activity

Activity: Individual

The studies in this thesis report about *information seeking* as an online coping activity (paper 2, 3 and 4). However, a broad picture of patients' information seeking behaviour will not be captured only in terms of the active, dedicated, and target oriented ways of seeking. To get a more fine-grained picture it is relevant also to illustrate that "other modes of "searching" do take place" (Wilson, 1997, s. 562). To capture different forms of information behaviour features of the general model of information behaviour (Wilson, 1997) is applied (passive attention, passive search, active search, and ongoing search).

The results suggest that we should consider *active as well as passive forms* of information seeking (paper 2). This means we should pay attention also to those occasions when there are no information seeking intended (like when watching a TV program or reading a newspaper or magazine) but patients get information about relevant online sources nevertheless (passive attention). Another form of passive search mode is when information is encountered unintentionally when the patient actively search for *other* types of information (passive search).

Regarding active search for online information a common strategy among the patients is to enter the Internet by using regular search engines (like Google, Yahoo, AltaVista, etc.) and type in the diagnosis (paper 2). Often this procedure results in a great number of hits difficult to make sense of and structure. Despite the obvious difficulties, this initial step is followed by procedures where the patient start to view the web pages in the beginning of the hit list, then following links from one page to another. The patients' perceived confidence in the web page producer/owner influence the decisions to enter (or to maker further use of) the pages.

In addition, experienced medical information seekers tend to apply an ongoing search mode where they use a few favourite web sites on a regular basis representing resources they find relevant and reliable. Occasionally they perform additional active searches to keep informed about new sites developing or other forms of updates.

When considering the different ways of information seeking some modes might be considered more beneficial than others. However, regarding information seeking outcomes several aspects should be taken into account revealing a complexity that cannot easily be reduced to the dichotomy of pros and cons. According to the results (paper 2), passive search modes naturally generated a limited and random set of medical information. However, it also

provided the seeker with a set of medical information easy to grasp and manage. On the other hand, active forms of seeking brought almost unlimited amount of information increasing the risk of “information overload”, causing some patients to experience confusion, frustration, and disempowerment.

In addition, in some cases patients’ limited online information seeking can be related to a limited knowledge of technology/Internet use. However, among the participating patients this was also connected to coping involving avoidant or awaiting strategies (Lazarus & Folkman, 1984; Snyder, 1999). On the contrary, other patients performed extensive information seeking reflecting their personal strategy to cope with the stressful situation.

Besides information seeking, the findings show that online *grouping* are important to the patients from an individual perspective as well (paper 3, 4 and 5). On the Internet, their grouping efforts involve participation in existing spaces (like discussion boards provided by patient associations or other actors) or activities to initiate patient managed self-help groups (paper 3 and 4). The grouping activities involve the possibility to get *social support* from other sufferers. However, the findings suggest social support should be recognized as a diverse set of support. Using the terminology proposed by Schaefer et al. (1981) on different forms of social support this concern *informational* support involving additional information about symptoms, experiences of particular examinations, or treatments. Other forms involve *tangible* support such as direct forms of aid like information about particular clinics, doctors, and/or treatments. Additionally, the patients search for *emotional* support like recognition, reassurance, and human understanding.

Intuitively social support refers to people involved in forms of active communication. However, the findings indicate that social support as a coping strategy not necessarily involves direct contact or interaction between patients. That is, sometimes the patients find the support they need just by reading others stories and anonymously (without participation) follow ongoing discussions (paper 4).

In addition, the social support relates to *facilitating others*. The studies of the self-help groups show that altruistic behaviour (Vaillant, 1977) is a contributing driving force of the groups (paper 3 and 4). The initiators want others to benefit from their coping activities, bringing as sense of strength and pleasure back. Also, some participants in the groups are motivated by the possibility to help others and experience this as a healing force. Altruistic forms of coping thus works in two directions. That is, by helping others the patients help themselves.

Activity: Group

A way to capture patients’ activities in online self-help groups is to examine the group purposes (Baym, 1995; 1998) (paper 4 and 5). This approach indicates what patients find important and illustrate variations among self-help groups in respect of their motivation. The groups have several purposes where some are

fundamental for the groups' existence while others emerge through participant interactions (ibid.). In general, the purposes were communicated either directly, like in text on the "welcome-page" and/or by the web page design (like linking to certain pages).

A basic purpose of the participating self-help groups is to *inform* and help patients to become knowledgeable about the disease and from a patient perspective reduce stress and uncertainty that follows when facing illness. Major parts of the information available are the results of the initiators efforts to seek and structure (sometimes also to translate) information about the disease. By means of the extensive set of information, the self-help groups constitute a complementary source of information aiming to meet patients' varying factual and social information needs. In the groups, it is crucial to provide the initial general information that patients might require as newly diagnosed. However, even more important is the idea to provide specific and more detailed information further supporting patients' decision-making. Information breadth as well as depth is thus important.

Closely related is the group purpose to *learn*. This purpose involves the ambition to strengthen the patients' position in the healthcare system. The idea is to help patients become informed and increase their abilities to engage in discussions with doctors and healthcare professionals on more equal terms. To learn about the disease is thus believed to increase patients' options, and to support them in making informed choices in the healthcare system. Efforts to serve as a learning environment become visible for example, in the expressed purpose of the group found on the web pages emphasizing the idea of patients becoming "their own expert". In addition, extensive lists of links to other sources of medical information sometimes referred to as "recommended readings" express the purpose.

The purpose to offer contact and *social support* is crucial in patients' online self-help groups. This purpose is clear from the arrangements of different interactive facilities (like e-mail lists and discussion boards) and/or by the stated purpose that "the group exists for the participants mutual support". The general idea is to promote discussions and personal interactions and in this way serve as a meeting place for fellow patients. Patients are encouraged to join the dialogue and information on the web pages as well as in the ongoing discussions emphasize the benefits of participation. There are also well-described technical and social instructions for how to participate. The groups promote active partaking but vary regarding acceptance of other behaviour, like to passively follow discussions and read about others experiences.

In most of the participating groups, the focus on social support is highly emphasized while in a few groups the idea to serve as a means to *influence the public opinion* is even more important. Since some diseases are not as well-known the idea is to create "disease awareness" among patients and in society in order to affect the ways the healthcare system and/or other actors (like public authorities and

insurance companies) act towards the patients. Beside medical facts about the disease, issues related to patients' rights are the topic of much of the information available. For instance, there is information about legal cases concerning the disease and about specific cases that have attracted attention in mass media. In addition, there are reprints of newspaper articles available. In addition, the intention to influence the public opinion becomes visible in the expressed request for patients to participate in a public discussion about the situation (social and medical) for the specific patient group.

Activity: Society

By searching the Internet patients' learn about medical issues as well as patients' rights and they increase their general and specific knowledge of the illness situation (paper 2). Further dimensions are added to their knowledge as they participate in online discussions about their illness (paper 3, 4 and 5). In general, patients therefore *contribute to the emergence of the patient role* by their online coping activities. This means that by coping online the patients move towards the idea of the informed expert patient. In addition, this relates to patients possibilities to *challenge the medical expertise* as well.

Further, patients' coping online contributes to increase the general awareness about the patient situation in society at large. More specifically, by online activities, the patients *influence the public opinion* (paper 5). Fellow patients get in contact with each other and messages about how to act and what to demand from healthcare is spread. An example is a patient treated with a new and perhaps controversial treatment. Her experiences discussed in the self-help group might affect also what many other patients will ask for or refuse. Another example is patients' collaborative online efforts in making a disease known by such efforts as participating in a public debate about the specific terms for a patient group.

By coping online patients *act as producers and consumers of medical information*. First, this means patients have the possibility to access largely the same set of medical information as do healthcare professionals (paper 2). Second, this refers to patients contributing to the collected amount of medical information publicly available online. This is not necessarily a deliberate process since patients contribute to the available set of information with their illness stories and/or contribution in discussions online (paper 4 and 5). Other patients, however, more intentionally put up web pages containing extensive medical information (3 and 4).

In addition, by online coping activities patients *take on a technological lead in relation to healthcare practice*. The findings illustrate how patients by means of the Internet learn about how to utilize the technology for their purposes (paper 3 and 4). For instance, by searching for information on an international basis they learn about features of web sites regarding content as well as forms (paper 2). This contributes to patients developing ideas of how Internet can be used and how technology can support their needs.

However, complementing the picture of patients as active Internet users the results reveal different preconditions to cope online (paper 1 and 2). This means that not all patients have the necessary resources to use the Internet to learn about medical and practical issues, and to make use of this in their own care and treatment process. Thus, online coping activities can be viewed as a phenomenon that further *highlights issues of the digital/medical divide* in society.

5.3.3 Mediation

As mentioned earlier coping with illness is not an isolated phenomenon. Therefore, in the model of coping online the concept of mediation captures the mutual influence between coping context and coping activity. The following provides significant examples from my research illuminating the process of mediation on the individual, group, and society level.

Mediation: Individual

The findings illustrate that both information seeking and grouping as an online coping activity help patients to get informed (paper 2 and 3). This influences the patient context as it *supports personal knowledge development* of the illness and further equips the patient to cope with their situation on a daily basis and to act against healthcare providers (paper 1 and 5). In addition, the personal knowledge development influences patients' technical abilities to develop their online coping. For instance, the results of the studies indicate that patients that initially were unfamiliar with the Internet gradually developed their technology use (paper 4).

On the other hand, paper 2 illustrate that the Internet contains vast amounts of medical information. Consequently, information seeking as an online coping activity involves the risk for patients to get overwhelmed by the information or to become misinformed, frustrated, and confused. This influences the context in a more negative way and *requires patients to develop strategies to manage situations of information overload* as well. For instance, future coping activities might therefore be coloured by even more efforts to search online in order to structure the information found or it might lead to avoidance of information seeking on the Internet (paper 2).

Further, coping by *facilitating others mutually influences the individual coping context* of the helper and the helped patient. The helper feels strengthened as their achievements bring new meaning to their lives (paper 3 and 4) and the actual help received affects the coping context of the helped patient.

In addition, the information seeking contributes to *patients taking on new or additional coping strategies* (paper 1 and 3). For instance, while seeking information about their illness patients found web pages for getting in contact with others. Learning about these Internet sites inspired them to cope by getting social support from others and later to facilitate others as well (paper 4).

Mediation: Group

This thesis suggests patients' initiation of online self-help groups are the results of individual coping processes involving forms of information seeking and a gradually developed search for contact with others (paper 3). When these forms of groups are started and developed, they *contribute to the emergence of new forms of coping resources online*. This is an example of the process of mediation between context and activity.

Coping by participation in self-help groups further illustrate the process of mediation between the coping context and the activities as it *supports the ongoing development of the self-help groups* (paper 4). For example, they evolve by the illness stories and the information added by its participants. In addition, coping in the self-help groups affect the social relationships and the development of identities in the groups. The ongoing activities in the groups contribute to the development of different group purposes as well. In addition, initiating and participating in self-help groups often involve altruistic coping behaviour as well (paper 3 and 4). By providing support the helping patient influences her own situation as well as others. These coping efforts contribute to the development of the self-help groups as an emphatic and supportive context for online coping.

In the process of mediation, the evolving online self-help groups influence the online coping context as they serve as *complementary healthcare information resources* offering patients contacts on a peer-to-peer basis and information based on real illness experiences. An additional example of mediation relates to this spreading of information in the self-help groups. When patients provide their stories with experiences of symptoms, examinations, treatments, and so on they add to the collected amount of medical information on the Internet. This means the self-help groups become an additional source of online information that patients must consider and assess which some patients find frustrating. In addition, patients' stories can affect other patients' coping in a negative way since they are exposed to information that they do not feel ready for. Some patients prefer information in line with the development of their illness and therefore avoid self-help groups (paper 1 and 2). Also, the discussion and exchange of information involves a potential risk of diffusion of misleading information.

Mediation: Society

On the level of society, mediation between context and activity becomes a part of ongoing social processes (Aldwin, 1994). One such process is associated with *the development of the patient role* and a market and management discourse in the healthcare system (Nordgren, 2003). This discourse becomes as a part of the coping context where patients are referred to as customers and active partakers. When patients act in line with related social and cultural expectations for coping (like seeking information in order to act the informed patient) it influence the societal context for further coping. For instance, when patients cope online they develop their knowledge and increasingly challenge the medical expertise and

professional healthcare practice arrangements. This refers to patients demanding particular treatments or examinations due to what they have learned during their online coping efforts (paper 5).

In addition, the findings show patients' coping online *increases the availability of detailed and specific medical information* about what it is like to live with a certain illness (paper 3 and 4). This adds a particular type of information difficult for healthcare to offer. As patients provide their information they influence the larger coping context as more patients can use the information for their own coping purposes (paper 5).

In general, this means patients various coping activities online contributes to the process of *forming the Internet as a coping arena*. As patients cope online they are engaged in activities where they search, interact, and create. As both consumers and producers of information and services (paper 4 and 5), they support an increased awareness of Internet in society as an important part of disease management resources.

However, it is important to keep in mind that patients' various online coping activities influence the societal level of the coping context by reinforcing the situation of *users and non-user of the Internet*. This refers to the previously mentioned situation where the digital divide becomes even clearer and where some patients, by means of their coping online obtain advantages in relation to other patients (paper 1 and 2).

5.4 IMPROVING INTERNET USE IN THE PATIENT – HEALTHCARE RELATIONSHIP

The patient activities explored in this thesis illustrate that the Internet has developed into a complementary resource when coping with illness. On a general level, this involves opportunities for patients to get informed from a factual as well as emotional and psychological basis. Of course, there are many challenges involved as well, such as risks of misinformation, lack of healthcare support and issues of digital/medical divide (as mentioned earlier). Against this background and the growing expectations of Internet as a matured resource in healthcare (c.f. Johnson & Ambrose, 2006; Demiris, 2006; Murero & Rice, 2006; Rice & Katz, 2001) it is relevant to reflect upon the implications of patients' use of the Internet for the design of information technology use and for healthcare practice. Therefore, the following presents my interpretation of the meaning of patients' coping online when improving Internet use in the patient – healthcare relationship. The specific form of technology development considered is emergent forms of Internet support between patients and healthcare involving spaces for health information and interaction between treating clinic and patients as well as between patients (see section 2).

5.4.1 Implications for design of Internet use

Learning from the patients in this thesis a clear message is that the design of Internet support in the patient–healthcare relationship should strive for *flexible and personalized* forms of Internet use. This means the design should aim for solutions meeting patients’ different preconditions and needs. Taking on such a challenge calls for attention of patients’ heterogeneity and a multi perspective approach towards the patient situation (paper 1). For instance, this involves considerations of the particular medical diagnosis involved. A fatal disease is likely to generate different requirements than do a life long disease or stigmatizing diagnoses, etc. In addition, patients’ demographics call for specific design considerations where children and adolescents is likely to have other needs and demands of Internet support than elderly people suffering from the same illness. Similarly, physical and social abilities for system adoption and use should influence design decisions. This refers to patients’ different knowledge of IT/Internet use involving the challenges of finding solutions to reach the difficult to reach. Further, the use of the Internet is related to patients’ preferences for technology use for health related purposes. This means the development of technological solutions should not solely focus on those patients applying an active and participative strategy. Instead, the design should also explore how to support patients that apply somewhat more hesitant and awaiting strategies. Possible solutions could involve the invitation of the patients to a stepwise learning process on the particular subject.

In association, design departing from patients’ heterogeneity involves efforts to support different forms of coping strategies (paper 1, 3 and 4). According to this research, this involves design for information seeking coping. The results of the thesis show that patients largely are thrown upon their own resources to search the Internet for medical information (paper 1, 2, 3 and 4) and that direct support from the healthcare is limited. This means patients have to rely on their own skills and preferences to find information and to judge the usefulness and trustworthiness of the information. This involves the risk of encountering misleading or irrelevant information. In addition, there is a risk of patients getting too much information and experience information overload. This implies that design efforts should be made to support patients in their information seeking coping and provide forms of *online guidance* helping patients to find and assess information on the Internet.

In addition, the findings of this thesis suggest that medical information presented on the Internet should provide dimensions of both surface and depth of information (paper 1, 2, and 5). In particular, this implies functionalities that provide access to *general as well as specific information* about a certain illness. This would provide a possibility to get the initial medical facts (like causes, symptoms, treatments, and prognosis) as well as to deepen the knowledge about the individual case of illness (such as the relationship between personal test results and ongoing treatments).

Further, the findings of patients' coping online propose that an additional design aspect is to develop solutions for *online dialogues*. This implication has two dimensions. The first dimension concerns the possibility for patients to interact with fellow sufferers for mutual support and human understanding. Here, learning from patients' forming online self-help groups several issues become important. First, it is important to provide for different forms of participation and learning styles (paper 4). That is, some patients might want to interact in closed online spaces available for members only while others, for some reason resist memberships or registration procedures and prefer to participate in open discussions only. Open discussion is also beneficial for patients that do not want to take active part in discussions but instead learn from the ongoing discussion they may follow (paper 3 and 4). Second, the design must allow for anonymous participation. This can be particularly important considering stigmatizing diagnoses. Designing Internet use that provide these possibilities for online dialogues would support patients coping strategies involving the seeking of social support as well as altruistic forms of coping.

When coping online by means of grouping activities, patients are mainly thrown upon their own resources as well (paper 3, 4 and 5). This might give the impression that patients handle the issues of getting in contact with each other well on their own and that there is no need for healthcare to get involved. Some commentators argue that patients' discussions should take place without the interference of healthcare professionals (Preece, 1999) since that would restrain the patients' discussions. However, the experiences of the performed research indicate that patients wish for an online dialogue involving healthcare professionals and that there is room for different types of complementary online resources. Further, the results show frustration among the initiators of the self-help groups for being an important online resource for many patients' but without medical competence or contacts with healthcare (paper 4).

In addition, for healthcare practice the initiation and management of online groups for patients' mutual support would provide an additional opportunity to learn about the patients and different aspects of medical and everyday life living with illness (paper 3 and 4).

This relates to the second dimension of the design implication for online dialogues referring to patients possibilities for online contact with healthcare professionals. Today it is possible for patients to interact with so-called "cyberdoctors". They are physicians, active online providing patients with additional information and advice. However, the findings of this thesis indicate that patients' require functionalities to be able to get in contact with their treating doctor or clinic for additional questions or for clarifications about information found on the Internet (paper 3).

5.4.2 Implications for healthcare practice

Regarding Internet use in the relationship with the patient, healthcare organizations has been criticized for being slow adopters of online technology (Johnson & Ambrose, 2006; Kiley, 1999; Rice & Katz, 2001; Morahan-Martin, 2004; Murero & Rice, 2006; Wen & Tan, 2003; Wilson, 2003). In addition, the critique has considered the low Internet awareness in healthcare regarding how the Internet can be used and the information available online. Contrasting this situation stands the high expectations of online applications to support healthcare in facing future technological, demographical, and economical challenges.

The findings of this research further stress the demands on healthcare practice to *increase the Internet awareness*. This involves the development of increased knowledge of patients' activities online and their requirements for Internet use. Additionally, and as mentioned in the previous section, the results of this thesis indicate needs for healthcare to *develop the online participation* in order to meet patients online and to support their ongoing use of the Internet.

Patients, on the other hand, have generally been described as rapid Internet adopters (Demiris, 2006; Johnson & Ambrose, 2006) employing various forms of online resources. As patients learn from these sources, healthcare practice will *increasingly meet well-informed patients*. The results of this thesis support this as well, suggesting that patients by means of the Internet individually and/or collectively strengthen their position to act against healthcare (paper 2, 3, 4, and 5). For instance, by exchanging information and experiences, the patients influence knowledge about available care and treatments for particular illnesses (paper 4 and 5). Additionally, the patients coping online influence the public opinion influencing the disease awareness among patients and in society at large (paper 4 and 5). However, despite the increasing possibilities to learn from Internet use we should be mindful that not all patients become well-informed. As mentioned earlier, there is a vast amount of medical information on the Internet and it is difficult for patients to sift out what is relevant and trustworthy (paper 1, 2, and 4). Therefore, there is a risk for healthcare meeting patients being misinformed, frustrated, and confused as well.

Further, coping online means *patients become users and producers* of medical information (paper 3, 4, and 5). For healthcare practice, this involves patients that directly participate in shaping the content of medical information. For example, they do so by searching, bringing together, translating information, and by creating homepages about particular diagnoses. Additionally, patients use and produce medical information by participating in online discussions about the illness and patient situation. Together this becomes additional information sources to consider for patients as well as healthcare practice. When patients contributes to the amount of medical information available the lay knowledge increases. This can benefit patients as they get access to more information related to direct

experiences. However, there is a risk of incorrect or irrelevant information dissemination.

In addition, patients' coping online contributes to *additional technological demands on Internet use* in healthcare. More specifically, patients use various forms of online technology use such as different interactive facilities and different medical databases on a national as well as international arena (paper 2 and 4). This suggests patients develop an Internet experience that will challenge healthcare practice in the process of developing Internet use. For example, patients coping online learn a lot about what the technology can offer in terms of content as well as use. This implies that patients increasingly will demand healthcare to offer more specific information and communication comparable with what patients experience in their contacts with other societal institutions, public authorities, companies or international web pages.

The different individual and collective online coping activities create conditions for patients to *challenge the medical expertise*. However, this is not to say that the relationship between patients and professionals by means of the Internet is changed into one among equals. Instead, this suggests that healthcare practice increasingly will meet patients that question medical competencies and put new demands on healthcare delivery.

Finally, this thesis focuses on patients actually using the Internet. However, it is important to keep in mind that not all patients share the benefits of coping online as many lack the necessary resources to participate on the Internet. Therefore, patients' coping online *accentuates the issues of digital/medical divide* as an important challenge for healthcare practice to manage.

6. CONCLUSIONS

Against the background of limited studies of patients' online activities this thesis focus on how chronically ill patients use the Internet for illness management purposes. The thesis contributes by; i) providing *a comprehensive picture of patients' use of the Internet as an online phenomenon* ii) *introducing a model of coping online supporting our understanding of this particular IT/Internet use* and iii) providing *implications for further development of Internet use in the patient–healthcare relationship as well implications for the healthcare practice at large*.

In the thesis, patients' use of the Internet is conceptualized and problematized using ideas departing in coping theories. By means of the proposed model of patients' coping online a comprehensive picture occur involving individuals' internal and external factors shaping the *coping context* serving as a basis for the online coping activities performed. The *coping activities* captured in the thesis are: *information seeking, seeking of social support, and to facilitate others*. In addition, the model of coping online emphasizes the process of mutual influence (*mediation*) between the coping context and the coping activities. The concepts of context, activity, and

mediation constitute the critical issues guiding the analysis of the research results and contributions. The analysis departs from individual use but reaches towards collective efforts as well. Therefore, to structure the complexity of the phenomenon, aspects of *group* and *society* dimensions accompany the *individual* view.

Considering patients' use of the Internet in terms of coping, contributes with a human behavioural perspective on IT and Internet use related to a psychological reasoning about how individuals manage stressful situations. By capturing the use of technology as a part of human response processes when managing stressful events (like facing illness) this research emphasize additional driving forces of this form of IT use than social, cultural and technical.

In addition, the thesis contributes with implications for design of Internet use and for healthcare practice departing from the patients' experiences. This includes design proposals of information systems aiming to support an Internet use in the relationship between patients and healthcare. The main suggestions involve to develop *flexible and personalized Internet solutions*, to design spaces for *online dialogues*, to offer *general as well as specific medical information*, and to provide professional *online guidance* to relevant and reliable medical information. Regarding the implications for healthcare practice, the main implications are to *increase healthcare's Internet awareness* and *online participation*. Additional implications concerns the development of *well-informed patients*, acting as both *users and producers* of medical information, putting *additional technological demands* on healthcare Internet use, and strengthening their position to *challenge the medical expertise*. Additionally, coping online reveals patients' different preconditions to benefit from Internet use accentuating the issues of *digital/medical* where some individuals strong on resources get access to healthcare on different conditions than others.

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Part II

THE PAPERS

EXPLORING E-PATIENTS' HETEROGENEITY: TOWARDS PERSONALIZED E-HEALTH APPLICATIONS

Ulrika Josefsson

Abstract

Some of the major future healthcare challenges are related to demography, finances and the technological development. In search for solutions the field of 'E-health' is often discussed. Lately, in these discussions there has been a focus on the importance of creating patient-centred applications. Associated with the democratisation of the healthcare service and the development of "the informed patient" an important part involves the accomplishment of increased personalized medical information online. By exploring E-patients' heterogeneity, this paper aims to support the development of patient-centered E-health applications. Using a qualitative approach, the paper reports from 25 in-depth interviews performed with Swedish patients and representatives of patient associations. By means of theoretical ideas from information science, four important components of E-patients' information use environment (People, Problem, Setting, and Problem resolution) serve as instruments to illustrate and exemplify E-patients' heterogeneity. The results draw a complex and dynamic picture of the E-patient context introducing a dimension of personalization reaching further than patients' general online activities and individual medical data. This dimension of personalization is discussed in relation to tentative implications for the development of patient-centered E-health applications.

INTRODUCTION

Healthcare is facing great future challenges often associated with three main factors (Wen & Tan, 2003; Wilson et al., 2004). First, the finance factor related to limited budgets together with concurrent demands to maintain full service and quality. Second, demography which concerns the expected development of an

aging population with more people living longer, which is believed to involve increased pressure on healthcare delivery. The development of new technology is the third factor involving demands on healthcare from society and citizens to adopt new technology for information and communication. In order to deal with these factors the development of 'E-health' is suggested as an important component (Eysenbach & Diepgen, 2001; Wilson et al., 2004). 'E-health' is a wide concept referring to various forms of information technology use in the healthcare system (see Oh, et al., 2005). However, in this paper the specific forms of E-health solutions at target are emergent forms of online support for patients' disease management and communication with healthcare. Examples of this form of technology include web portals for medical information or systems for patient participation in medical decisions such as online access to the ERP (Electronic Patient Record). Other examples include online health education programs and healthcare managed online spaces for interaction between healthcare and patients. Applying a patient perspective the aim of this paper is to contribute to the development of such forms of E-health applications.

Patient-centered approaches to this technology development are proposed (Klein-Fedyshin, 2002) involving increased personalization of the medical information online (Doupi & Van der Lei, 2002). This is associated with the democratisation of the healthcare service and the development of "the informed patient" (Henwood et al., 2003). In this process, the patient role is shifting from a passive receiver towards an active consumer making his/her own healthcare decisions (Klein-Fedyshin, 2002). However, Berg (2002) argues recent intensive focus on patient-centeredness risk the concept to become nothing more than a cliché. Therefore, we need to recall the essence of true patient-centeredness: "It implies ensuring a patient trajectory whose course is first and foremost determined by the patient's problem and needs, rather than by the way the organizations involved happen to have subdivided their functions" (Berg, 2002, p. 34). For the E-health development, this indicates a need to move closer to patients as prospect users and to learn more about their heterogeneity.

Learning about E-patients, previous studies focuses on their use of web portals (Hansen et al., 2003) and web resources integrated in the treatment process (Leimeister, et al, 2004). Others have explored patients' online information seeking behaviour (Henwood, et al., 2003; Morahan-Martin, 2004) and participation in social support groups online (Shaw et al., 2000; Wright & Bell, 2003). However, most studies focus on E-patients either as a homogeneous group or on E-patients suffering from a specific health condition. These perspectives are important, but the patient view would benefit from complementary approaches illustrating the fine-grained picture of the E-patient context. Here such approach is believed to contribute by providing differentiating as well as common aspects of the patient situation. Therefore, taking a patient perspective this paper contributes with factors of E-patients'

heterogeneity important to feed into the discussion on emergent forms of personalized E-health applications.

To accomplish this, a qualitative approach is applied and the paper reports from 25 in-depth interviews with Swedish E-patients and representatives of Swedish patient associations. The specific group of patients focused on are suffering from various types of chronic diseases. The selection is motivated by chronically ill patients as long terms users of the Internet in dealing with their illness and therefore an important category to examine and support with patient-centered E-health solutions (Klein-Fedyshin, 2002; Shaw et al., 2000).

Ideas from information studies and Taylor's (1991) approach on information transfer structure the empirical data. According to Taylor (1991), there are three main approaches to the study of information transfer. First, the technological approach focusing issues like structure and functions of information systems. Second, the content-driven approach oriented towards classifications and ordering of knowledge and information. These two should be complemented and informed by a third approach: user and the uses of information and the contexts in which the users are operating. These contexts Taylor denotes as "Information Use Environment" (IUE). Taylor (1991) then suggests four categories to describe an IUE: People, their Problem, Setting and Problem resolution. For the purpose of this paper, these categories are believed to form a useful tool for capturing the data and the specific heterogeneous context of patients as Internet adopters and users in problem-intensive situations.

The paper opens with an overview of the performed research study followed by an introduction to Taylor's IUE model. Using the model, the results of the study are then presented. A discussion on the tentative implications for increased personalization of E-health tools closes the paper.

THE RESEARCH

The idea to capture E-patients as a heterogeneous group involves the ambition to search for a broad empirical basis. Hence, the empirical data in this paper have been collected from three related research studies (table 1).

Study/Duration	Diagnosis		Question areas
1): 7 representatives of patient associations/ February – March 2000	Diabetes Hearing disorders Psoriasis Parkinson disease	Tourette syndrome Whiplash injury Rheumatism	Purpose of the Internet pages/ patients' use of the interactive facilities/ medical information needs/ opportunities and challenges of Internet use/ future use of the Internet
2): 10 patients running self-help groups on the Internet/ March – May 2002	Whiplash injury Polycystic Ovarian Syndrome (PCO) Endometriosis Multiple sclerosis (MS)	Chronic Fatigue Syndrome Chronic prostatitis Fibromyalgia Panic disorder Thyroid disease	Patterns of use of the Internet for medical information/ pros and cons/ information – communication needs and demands/disease specific needs
3): 8 patients using the Internet to cope with their disease/ November 2003 – February 2004	Prostate cancer (PC)		The specifics of using the Internet for medical information about PC/ pros and cons/ information – communication needs and demands for patients with PC

Table 1. The performed interview studies.

The purpose of the first study was to get an introduction to patients as adopters and users of the Internet for medical information. Therefore, the point of departure was Internet use by patient associations and their contacts with patients. This approach was chosen in order to analyse the online activities of large and varying patient groups. Using four lists on the Internet containing Swedish patient associations, the provision of interactive online facilities guided the selection. Seven associations were contacted each representing a certain diagnosis. The associations are non-profit organisations for patient support. The number of members and financial basis varies with the largest associations having about 50,000 members and the smaller 2,500 members. The larger associations are receiving grants for some of their work while the smaller are depending on voluntary work. The interviewees serve as chairmen or official informers at the associations. Also, they have personal experiences of the disease/injury and of being a patient using the Internet for medical information.

To get closer to patients and their perspective on Internet use the second study involved patients that share the experience of initiating self-help groups on the Internet. The groups offer a set of web pages with a variety of medical information about a specific disease together with interactive facilities like discussion boards or e-mail lists. The purpose of the groups is mainly to provide patients with medical information and the possibility to get contact with fellow sufferers for exchange of experiences on a peer-to-peer basis. The idea was to capture “patients in action” on the Internet meaning that the interaction and communication activities performed were central. Therefore, the selection of patients as initiators and managers of self-help groups was guided by the

interactive facilities provided and the “patient activity” that occurred in the self-help groups. In addition, to get a broad patient perspective the ambition was to let the selected patients represent several diseases and health conditions. Using regular search engines 10 self-help groups were selected.

The third study consisted of interviews with patients suffering from prostate cancer (PC). The aim was to focus on patients with a shared diagnosis to provide a deeper example of the specifics of the situation of facing illness. In short, PC mostly strikes elderly men and more than two third are over 70 years old. This type of cancer is the most common cancer among men. In Sweden, there are about 9,800 new cases each year (Swedish Cancer Society, 2006) and the American Cancer Society (2006) estimates that there will be about 234,460 new cases of PC in the U.S. in the year 2006. The incidence of PC makes the patients an important group to follow also when it comes to Internet use and the specific requirements for online activities related to the diagnosis. Cooperating with the Department of Oncology at the Sahlgrenska University Hospital in Göteborg (Sweden), contacts with prostate cancer patients were established.

Performed as a conversation between the researcher and the respondents a semi-structured approach with a few specified question areas guided the interviews. The participants were guaranteed anonymity and the names used in the presentation of the data are fictitious. The interviews lasted for 40-75 minutes and were tape recorded and transcribed verbatim. The data were analysed using an inductive process where the material has been read and reread searching for patterns and features (Silverman, 1993). The process was carried out iteratively in two main stages. The first stage involved the identification of general patterns and features running through the data. The second stage involved sifting out additional patterns and features on gradually more specific levels. Further, the process of analysis involved the seeking of patterns within each performed study as well as across the studies. Also, the analysis was guided by the principal aim to provide significant examples of the phenomena rather than to quantify and to generalize from the collected material.

INFORMATION USE ENVIRONMENT

Taylor (1986) define Information Use Environment (IUE) as “the set of those elements that a) affect the flow and use of information messages into, within, and out of any definable entity; and b) determine the criteria by which the value of information messages will be judged” (p. 25-26). To capture the IUE Taylor (1991) uses four categories: people, their problems, settings and problem resolution (table 2).

Based on an intuitive understanding of their information behaviour Taylor (1991) categorizes People in different classes: the professions, the entrepreneur, special interest groups, and socio-economic groups. In terms of this

categorization, E-patients are here considered a “special interest group” assuming their specific interest in their disease and related issues. To support the description of ‘people’ Taylor uses demographic (age, sex and education) and non-demographic characteristics (like preferences for technology use).

Problem refers to characteristic problems considered important by the specific set of people. However, to understand the specifics of the problems it is necessary to capture the underlying problem dimensions (Taylor, 1986). The problem dimensions are the specific features of the problems and serves as a basis for judging the importance of information. Further, problem and their dimensions change over time as the conditions alter and new information is obtained (Taylor, 1986). For the purpose of illustrating E-patients’ IUE ‘problem’ and ‘problem dimensions’ in the following concern the different diagnoses and the related characteristics (stages, phases, treatments, side effects, etc.).

Setting concerns the physical and psychological aspects of the users’ environment. Taylor (1991) identifies four general aspects. The first concerns the values and attitudes of the environment. In Taylor’s example environment concerns the organizational and work related context and he calls this aspect ‘Importance of organization’. However, regarding E-patients a more intuitive way to examine this aspect of setting is to consider it from a societal perspective involving ideas of the democratisation of the healthcare and the changing patient role. The second aspect of setting is domain of interest and concerns issues such as individual and collective patterns of information gathering and dissemination. Access to information is the third aspect and involves physical access (such as an Internet connection) as well as psychological access related to the value of personal sources (like personal memory, friends, relatives, colleagues and peers). Finally, the fourth aspect concerns the organizations’ history of information management and knowledge creation (Taylor refers to this as ‘History and experience’). In the case of E-patients’, however it is more fruitful to consider these aspects in terms of knowledge and experiences of Internet use involving computer literacy as well as skills of online medical information seeking and assessment.

The final category in Taylor’s model is Problem resolution and concerns what constitute typical resolution of problems for a set of people (Taylor, 1991). Problem resolution thus focuses on how E-patients cope with illness and the problem dimensions they are facing.

People	Problem	Setting	Problem resolution
<ul style="list-style-type: none"> - The professions, the entrepreneur, the special interest groups, the socio-economic groups - Demographic factors: age, sex and education - Non-demographic factors; preferences for media use and attitudes towards new technology 	<ul style="list-style-type: none"> - Characteristic problems - Problem dimensions 	<ul style="list-style-type: none"> -Values and attitudes in the user environment -Domain of interest -Access to information -Knowledge and experiences of Internet use 	<ul style="list-style-type: none"> -What constitute typical resolution of problems for a set of people

Table 2. Summary of the model of Information Use Environment.

E-PATIENTS' INFORMATION USE ENVIRONMENT

Using the concepts of the IUE model, this section illustrates the results of the study. However, regarding patients a useful way to apply the model for illustrative purposes is to depart from the illness and related problems. Therefore, the presentation of the results begins with Problem followed by People, Setting and finally Problem resolution. Table 3 below summarizes the presentation.

Problem and Problem dimension – diagnosis and related characteristics

In this section, a number of examples from the empirical study highlight E-patients' different 'problem' (diagnosis) and 'problem dimensions' (related characteristics). The first concerns the severe fatal disease such as various forms of cancer. For instance, patients diagnosed with prostate cancer (PC) are informed that they suffer from a severe and sometimes life threatening disease. If the cancer is in such a stage that treatment is available, the patient is also informed that he is expected to be active in the process of choosing between different forms of treatments (e.g. surgery or radiation therapy). Mike expresses the situation as follows:

“This (prostate cancer) is probably one of the most extreme diagnoses when it comes to information need. When you have been diagnosed, the doctor cannot say what treatment is the most appropriate one. He can very well say which one is directly inappropriate but medical science today cannot say what treatment is best for PC. This means that the patient – without any knowledge about the disease is supposed to decide what treatment he will have. Under such conditions there is an incredible need for information to make a choice so impossible not even the doctor can do it.”

A second example of different health conditions is the chronic life long disease. Here Multiple sclerosis (MS) exemplifies this category although several of the diagnoses represented in the study could be used as well. In short, MS often progress in phases and gradually lead to worsening of several of the central functions of the body often involving cognitive dysfunctions as well (National Multiple Sclerosis Society, 2004). Today, there is no cure for MS and the patient is reduced to take various disease-modifying drugs. Besides the need for social support and human understanding the disease involve information needs of how the development of the disease might turn out and how the patient can be supported in his/her everyday life. Maria was diagnosed with MS in 1996. She was then 26 years old:

“When I was diagnosed I tried to understand it all. I read everything. At the time there was little online information about MS directed towards patients.”

Maria’s needs for information and contact with others resulted in the online self-help group she is now managing. The web site of the group contains a lot of medical information about MS and patients are provided with the possibility to interact using the discussion board, the e-mail list or the chat. Some of the features on the website mirror the specifics of the disease and related information need. Maria continues:

“In the beginning, I didn’t know what could happen and the “symptom list” developed as I experienced my symptoms. It is the same with “treatments” which has been changed as new treatments have become available [...] On the e-mail list people get to know each other more and talk much about practical matters such as social insurance issues, wheel chairs etc. People ask for advice and so on. On the discussion board there is much more about symptoms. People write about there experiences and ask if others have experienced the same”.

The third example concerns the specific requirements of stigmatising diseases. Patients suffering from these types of diseases may benefit from approaching sensitive subjects using individual strategies. Kate running an online self-help group for patients with endometriosis reported about this:

“We noticed that there were many patients who didn’t want to join the e-mail list and we realised that this was connected to the stigma of the disease...since endometriosis is related to the more intimate parts of the female body not many women cry out that they have got this disease. It is still shameful. That’s why we left the discussion board open so they don’t have to sign on to participate”.

A fourth example is the type of illness characterized as “less-known” and/or “difficult- to-decide” disease such as chronic fatigue syndrome, fibromyalgia, or whiplash injury. Except the need for additional medical

information and facts, the situation also demands for recognition and acknowledgement of personal experiences. Kim highlights this:

“It is important to remember that many doctors say that this disease does not exist! They just say it is psychological. That’s what you say when you don’t know. So, for people with chronic fatigue syndrome it is extremely important to find others with the same strange disease”.

A final example is diseases involving relatives as main (home) caregivers. The Tourette syndrome (TS) is one example. This disease is a neurological or "neurochemical" disorder characterized by tics, which are involuntary, rapid, sudden movements or vocalizations that occur repeatedly in the same way (National Tourette Syndrome Association, 2004). Since the age of onset is before 18, the parents get a central role in the care and treatment of the patient. This specific parent situation is central for the participating patient association for TS. In their work they have noticed “*a desire for reliable information in Swedish about TS, specifically for parents of newly diagnosed children*” and that “*parents have a great demand for exchanging experiences with others in the same situation*”.

People - E-patients’ demographic/non-demographic characteristics

To explore E-patients’ IUE involve consideration of characteristics such as age and sex. For example, in the study the association for hearing disorders expressed that “in the contact with our members we have to consider that many are in their 70-ies not using computers”. Another example is patients with prostate cancer (PC). PC strikes in the ages around 70 and the patients are usually recognized as less frequent user of information technology and/or the Internet. Mike (67 years old) reflected on the use of the Internet by typical PC-patients:

“I get a lot of e-mails and often it is from someone asking about the disease for their father or grandfather. You see, often it is not the patient but the younger generations that use e-mail and Internet for information and communication”.

In addition, PC strikes men only. However, the treatment processes often involve strains on the general quality of life (such as incontinence and impotence problems) involving the patients’ partner as well. This contributes to specific needs of information and Tom says, “About sex and married life...well, it takes two to deal with this disease. It’s the man AND his partner”. In addition, for the women's diseases in the study related to infertility problems (like endometriosis and PCO) there were similar concerns.

Some of the patient associations have acknowledged the role of gender for information needs. Similarly, they have recognized age as a factor for varying needs of information. For example, the association for Parkinson disease have

initiated sub-groups called “Women with Parkinson” and “Young Parkinson”. In addition, associations for diabetes, psoriasis and, hearing disorders have similar subgroups for younger patients.

An additional demographic characteristic concerns education often recognized as a crucial variable regarding the extent of patients’ use of the Internet (Morahan-Martin, 2004). In the performed study the significance of education indicate the abilities to seek as well as judge the information found. For example, George (PC) is a physician and he reported being offered special online services: “*It’s a web portal for doctors where you can order coverage of articles in your field of interest*”. Michael provides an additional example:

“In my work as a distribution manager in an international company, I’m used to search for Information on the Internet and I know that the Internet is a source of knowledge. So for me it was not a big deal to get online. I do that quite a lot at work so it was nothing new”. (Michael, PC)

Further, besides the formal education the patients in the study emphasized the need of language skills, which were considered as crucial when using the Internet to deal with illness. Mike (PC) explained this: “The first thing is language skills. You have to now English...well, first you have to know how to handle a computer but then you really must have language skills in order to reach beyond Swedish web sites”.

The quotes above also touch upon preferences of computer and Internet use as an important non-demographic factor (Taylor, 1991). Even though the study reveals a general positive view on Internet use there was a common theme that “Internet should be a complementary information source” (Eric, PC) mirroring the need for personal encounters as well: “*I want to meet and to talk to the doctor in person*” (Ian, PC).

Setting - physical and psychological aspects of the E-patient environment

The initial aspect of Setting concerns the values and attitudes of the environment. In the study, this concerns the fact that E-patients’ activities are performed in an environment affected by the changing patient role. For instance, the patient associations in the study picture Internet as an important arena in support of this development: “*Naturally we hope that our efforts on the Internet will provide for an increasing number of active members staying informed about healthcare, treatments, research and policies, etc*” (association for rheumatism). Additionally, from a patient perspective John (PC) highlights online information and the changing patient role:

“Healthcare must make their web pages clearer and not so anonymous. I mean...healthcare stills see the patient as someone who is coming cap in hand ...the older generation still does... but the younger put new demands...”

Second, the domain of interest concerns issues such as individual as well as collective patterns of information gathering and dissemination. Using the Internet E-patients in general are often regarded as acting in their own interest. However, they may also be acting on behalf of the interest of a specific patient group, like when participating in online self-help groups. Mary, running a self-help group for whiplash injury illustrates this as follows:

“I think I have learned quite a lot about this [whiplash injury] so I wanted to try to help others as well...I know how bad you feel and this is a good way to help each other”.

The third aspect of Setting concerns access to information involving both physical and psychological perspectives. All of the interviewed patients had Internet access in their homes and none reported using publicly available computers. The interviewed representatives of the patient associations mirrored this situation of physical access also although they could not provide a complete picture regarding all their members.

Further, the psychological aspect of information access is illustrated by the following excerpts indicating the value of personal sources like family, friends, relatives and peers:

“I have a friend who has been through the same thing...so I contacted him and he gave me information and his story” (Mark, PC).

“I have two brothers suffering from PC and naturally we have talked a lot about this” (Michael, PC).

“The best thing is that I have got contact with so many other women. We have exchanged many common experiences. This has really meant a lot to me and I feel that I know so much more from the things I have learned from the others” (Linda, PCO).

Finally, Setting concerns knowledge and experience of Internet use illustrating the significance of E-patients' computer and Internet literacy to manage their disease and overall situation as a patient. The majority of the study participants were Internet literate but some found it problematic to use. For instance, Mark (PC) who is familiar with the use of computers from his work at a bank office still find the medical information online difficult to find. Therefore, he mainly visits web sites provided by his family or by healthcare even though he knows *“that there is a lot to learn out there but I am not really sure where to go or how to search”.*

Problem resolution – coping with illness

For several of the patients in the study the initial way to deal with the disease and the new life situation was to search for medical information. The information seeking seems to have a value in its own right. To search, read and sometimes also to translate and bring together the information thus became a strategy for problem resolution. Michael (PC) describes this as follows:

“I felt good to be out on the Internet. There was so much. I could surf, search and go through stuff and print it out. I made copies to my own computer so I had several hundred pages”.

Another way of problem resolution involved the search of medical information related to social support. In the study, this involved the search for human understanding and emotional support as well as information about how to manage the everyday life situation. In addition, the results of the study highlight two functions of social support as a strategy for problem resolution. The first function means a way to get actual help and support from fellow patients in the same or similar situations. This might occur in a direct way in discussion boards or e-mail lists where *“they get information and support as well as e-mail friends”* (Lucy, running a self-help group for panic disorder). Additionally, it could be in indirect forms by patients reading others stories of illness. Sylvia running a group for fibromyalgia expresses this:

“They look for contact with other patients. Some simply want to read. On the page “Others’ stories”, they can read about this [fibromyalgia] happening to other people as well. It is very comforting since you feel as the loneliest person in the world and you think that this happens only to me”.

The second function of social support involves an opportunity for patients to facilitate others. This means that patients are being helped not only by getting support but also by helping others. In the study, Maria suffering from multiple sclerosis describes this as:

“...it makes me happy to be able to help others. For me... I am past the worst... but I know how hard it was and every time I get an e-mail from someone who thanks me it is most rewarding ...it is a very satisfying feeling.”

Problem	People	Setting	Problem resolution
Diagnosis and related characteristics (stages, phases, treatments, side-effects, etc): <ul style="list-style-type: none"> - Severe fatal disease - Chronic life long disease - Stigmatising disease - "Less know"/ - "difficult-to-decide" disease - Disease involving relatives as main caregivers 	<ul style="list-style-type: none"> - Special interest group - Age - Sex - Education - Preferences and attitudes of Internet use in the patient – healthcare relationship 	<ul style="list-style-type: none"> - Values and attitudes related to the changing patient role - Personal interest – group interest - Physical access and personal sources - Knowledge and experiences of seeking and judging online medical information 	<ul style="list-style-type: none"> - Seeking online medical information - Seeking social support - Facilitating others

Table 3. Summary of E-patients' Information Use Environment

DISCUSSION

Personalized information according to individual characteristics is an important area for future development of E-health tools (Doupi & Van der Lei, 2002; Wen & Tan, 2003). Regarding patients' use of the Internet two main dimensions characterises the discussions on personalization. The first concerns patients' individual online medical information seeking (Morahan-Martin, 2004) believed to support their participation in the healthcare process (Wilson et al., 2004). However, it put great demands on the individual and critical commentators emphasize the risks of retrieving misleading information and of a digital divide leading to a medical divide (Eysenbach & Diepgen, 2001; Morahan-Martin, 2004). The second dimension concerns healthcare provided patient education (Klein-Fedyshin, 2002). An example is information from the ERP (Electronic Patient Record) linked to online healthcare resources to provide personal data (Doupi & Van der Lei, 2002). In short, this means personal material supports health education and the ability for disease management. As a complement, the performed study highlights an additional dimension of personalization illustrated by the IUE model. It adds to the others by providing a number of factors exemplifying patients' heterogeneity reaching further than the individual's medical data and general online activities. Following table 3, the discussion below outlines tentative implications for the development of personalized E-health applications.

Towards personalization of E-health applications

An initial factor of patients' IUE concerns their specific Problem (diagnosis) and problem dimensions (related characteristics). The results provide examples of differences of required scope of information due to the diagnosis. For instance, patients diagnosed with a severe fatal disease might demand access to detailed information to make adequate medical decisions (exemplified in the study by the prostate cancer patients) as well as emotional and social support. The psychosocial aspect is present also for patients suffering from chronic life long diseases. However, for this type of disease the patients might need a long-time online resource that can manage various information needs related to different stages of the disease. In addition, patients suffering from stigmatising conditions may need special attention involving the possibility to share their story with fellow sufferers in a secure way. In similar ways patients suffering from "less-known" or "difficult-to-decide" diseases may benefit from the possibility to get contact with others for recognition and relevant information. Finally, health conditions involving home caregivers put special demands on E-health solutions to meet their situation and needs for contact with others. In sum, these examples indicate a need for further analysis of the particular requirements related to different diagnoses when aiming for personalized E-health solutions. A few initiatives have been made to adjust the online support in line with the disease at target (c.f. Leimeister et al., 2004; Shaw et al., 2000).

As People in the IUE, patients form a special interest group sharing the interest of a health condition. However, several factors need attention. For instance, the demographical factors such as age and sex. Children and adolescents may have other needs and demands of an E-health tool than elderly people (c.f. Becker, 2004; Hansen et al., 2003). Similarly, gender has significance for needs and demands of online support. As illustrated in this paper this might involve gender specific aspects of the diagnosis. Further, men and women have been found to apply different strategies in their use of the Internet for medical information. For example, using a pencil-and-paper questionnaire (N=123) Vermaas & Wijngaert (2005) found differences related to gender in the processes of collecting and using online medical information. In addition, education and work situation is recognized as an important demographic factor influencing patients' use of the Internet (c.f. Morahan-Martin, 2004; Wilson et al., 2004). The present study mirrors this by participants using their professional competencies to utilize the Internet. In addition, there are non-demographic factors like patients' preferences of technology use to consider. The results of the study indicate that even if patients have the necessary resources to use the technology he/she might be hesitant when it comes to disease management. This points at the need to take into consideration patients' different views on the role of the human encounter in the patient – healthcare relationship and avoid tendencies towards technological determinism (Henwood et al., 2003). For

example, this involves taking seriously patients requirements for complementary online resources rather than replacements of existing forms of patient – healthcare communication.

The Setting constitutes an additional component mirroring patients' heterogeneous environment. For instance, the values and attitudes related to the changing patient role that surrounds patients' use of the Internet involves increasing demands on patients to participate in their healthcare process. However, as discussed above patients' information needs and care processes vary which indicate patients' special conditions should guide the development of E-health support (Wilson, et al., 2004).

Patients' domain of interests when acting in this environment is an additional aspect of the setting. In general discussions on patients' online disease management there is a tendency to focus on patients as individual users only (Morahan-Martin, 2004). However, this study points at the value of considering patients as acting both on personal as well as group interest. In the study, patients' individual information seeking efforts and/or interests in online support groups exemplifies this.

Further, the access to information is a part of the patient setting. For instance, the patients in the study had physical access to the Internet in their homes although this is not yet the normal situation for the majority (Morahan-Martin, 2004). In addition, Henwood et al. (2003) argue having a computer at home is not equal to access as general computer and Internet literacy together with social structures affect this as well. Also, this is related to knowledge and experiences of online technology use (see below) and calls for further attention to issues of 'digital divide' and a deeper understanding of the meaning of access. In association, there are psychological aspects of access that should be considered as well. This involves patients' ideas of and possibilities for complementary personal dialogues (with fellow sufferers, friends, relatives, etc) further enhancing the perceived validity and utility of information (Taylor, 1991). Finally, the study exemplifies patients' varying knowledge and experiences of online information seeking and judging of the information influencing the setting of their IUE. To meet patients' heterogeneity with E-health technology this is an additional aspect to consider. One strategy may be to develop online tools offering educative functions to support learning about the Internet as an information resource as well as to increase health literacy (c.f. Klein-Fedyshin, 2002).

The final aspect of patients' IUE is their form of Problem resolution. This concerns the different ways patients cope with the stressful and difficult life situation of facing illness. In the study, patients' extensive online information seeking efforts is one example. The participants indicated that the search efforts are important per se when coping with illness and several of the interviewed patients referred to the information seeking as a form of "therapy". However, the Internet offers a vast amount of information of varying quality aggravating

patients' possibilities to find useful information (Eysenbach & Diepgen, 2001). Considering their information seeking as a way of coping with illness may further fuel the discussions about the need of healthcare provided online guidance to reliable sources (c.f. Eysenbach & Diepgen, 2001; Morahan-Martin, 2004). In addition, when striving for E-health solutions meeting patients' heterogeneity other ways of problem resolution should be recognized as well. For instance, there are patients resisting additional information and/or just prefer to become informed in line with the development of the disease (Henwood et al., 2003).

Patients' seeking of social support is an additional form of problem resolution exemplified in the study. This indicates the value of patient-to-patient communication when coping with illness (Wright & Bell, 2003) even though it may find expression in different ways. For instance, the participants described that some patients seek direct contact with others through discussion boards or e-mail lists while others prefer to follow ongoing discussions without participation, or just to read others stories. In addition, the patients in the study indicated that social support may have a second meaning as well. This refers to statements about the benefits of being able to facilitate others as well. That is, some patients appreciated the possibility to help others and at the same time help themselves. Although, social support and to facilitate others are well known as forms of problem resolution (c.f. Leimeister et al., 2004; Shaw et al, 2000; Wright & Bell, 2003) there are still few examples of E-health technology involving facilities to support them. This indicates a need for additional studies on how these and other forms of problem resolution can be integrated in E-health applications to enhance patients' disease management capabilities.

CONCLUDING REMARKS

This study focuses on patients' heterogeneity as an additional aspect to consider when developing personalized E-health applications. A number of factors illustrate the heterogeneity and highlight the importance of flexible E-health applications considering the type of diagnosis and related specifics along with patient demographics as well as physical and social abilities for system use. This includes a further acknowledgement of patients' various forms of coping strategies when dealing with illness.

Further, exploring E-patients' heterogeneity requires well-adjusted analytical tools. This study suggests the IUE model as an example of a useful tool. The user-oriented approach developed to support the design process serves the purpose of this paper. However, originally concerned with organisational and work related settings occasionally make the model difficult to translate to an E-patient context. Without the frame of a certain organization issues such as, what problems to refer to the IUE at target or what level of analysis to use on the

personal environment, challenge the balance between the specifics of the group and the specifics of the individual in the group. This paper adds with some initial development of the model to increase its usefulness in non-organizational contexts.

For analytical purposes, the factors of patients' heterogeneity are treated in separate although they are intertwined. Also, aiming for a broad picture, this means many aspects are briefly mentioned though they demand a thorough analysis in their own right. In addition, other factors that due to the nature of the study have not been included might influence the picture (such as financial, technical, and cultural healthcare challenges related to the demands of personalized E-health tools). Finally, using a qualitative approach the presented study involves a limited number of interviews focusing on a specific type of patients and diagnosis. Complementary methods are required to explore the subject in a wider perspective.

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PATIENTS' ONLINE INFORMATION SEEKING BEHAVIOR

Ulrika Josefsson

Abstract

Patients are increasingly searching the Internet for medical information to cope with illness and a changed life situation. However, few studies have addressed patients themselves and how they find their way through the vast amount of medical information online. Therefore, with the objective to give voice to the patients, this chapter identifies and analyzes patterns in their online information-seeking behavior. Using a qualitative analysis of 18 in-depth interviews with Swedish patients, the chapter captures important components of the complex picture of patients' information seeking on the Internet. Informed by ideas from information science, the presentation of the empirical data is structured around features in Wilson's (1997) general model of information behavior. Three themes (accessing online information, social support, and information accuracy and applicability) derived from the empirical data serve as the basis for a discussion on the consequences associated with the search behaviors observed in the studies. Balancing factors (coping strategy, resource requirements, and online information seeking assistance) complement the discussion in order to provide a nuanced picture of the outcomes of the participants online information seeking.

INTRODUCTION

Lately patients' online activities have been the subject of substantial research efforts covering various aspects. Studies have concerned how patients become informed and empowered through online medical information (Dolan, Iredale, Williams, & Ameen, 2004; Morahan-Martin, 2004) and how this contributes to

patients challenging the medical expertise (Hardey, 1999) and creating new demands on health care providers (Rice & Katz, 2001). Other studies are directed towards specific features of online activities such as patients' use of cyber doctor services (Umefjord, Petersson, & Hamberg, 2003) or self-help groups (Josefsson, 2005; Preece & Ghazati, 2001). Additional examples of scholarly work involve the influence of Internet use on the patient-doctor relationship (Anderson, Rainey, & Eysenbach, 2003; Rice & Katz, chap. 8, this volume). Further, issues related to information-seeking behavior of online medical information have been explored. For instance, some have focused on information seeking among healthcare professionals (Zhang, Zambrowicz, Zhou, & Roderer, 2004) whereas others have considered strategies for online information seeking among health consumers (Eysenbach & Köhler, 2002; Warner & Procaccino, 2004). Some studies have considered the risks of such activities and directed our attention towards issues of how to deal with unreliable medical information online (Adams & Berg, 2004; Eysenbach & Jadad, 2001).

However, there are few studies that focus on patients themselves and their information-seeking behavior (Anigbogu & Rice, 2001; Leydon, Boulton, Moynihan, Jones, Mossman, Boudioni, & McPherson, 2000; Morahan-Martin, 2004; Murero, Ancona, & Karamanoukian, 2001; Napoli, 2001; Tang & Lee, chap. 6, this volume). Capturing how patients pursue their seeking activities online is motivated by the requirements for developing Internet use in the patient-healthcare relationship. The Internet is often pictured as an underused resource in this area (Rice & Katz, 2001) and the increasing demands from patients for online contact with healthcare and doctors has been pointed out (Wullianallur & Tan, 2002). To support the design of Internet use in this relationship, the patient perspective as prospect user must be taken seriously (Van't Riet, Berg, Hiddema, & Sol, 2001). Studying patients' online behavior is thus believed to be a fruitful way to increase our knowledge about the patients' situation, needs, and demands when adopting and using online medical resources. Consequently, the purpose of this chapter is to capture important characteristics of patients' search patterns and, in a wider perspective, support the design of emergent forms of Internet-based healthcare resources. It accomplishes this by taking the perspective of the patient, involving respondents with different diagnosis and search patterns.

Discussions on patients' use of the Internet have been criticized for being one-sided, often emphasizing the benefits of these online activities. Among others, Henwood, Wyatt, Hart, and Smith (2002) pointed out the need for a more balanced discussion that "map out a more complex picture of both information handling and Internet use" (p. 89). Therefore, the chapter aims to provide a nuanced discussion, derived from the empirical data about the consequences related to patients' online information seeking.

To accomplish this, the work is informed by lessons from information science on human information-seeking behavior. More specifically, Wilson's

(1997) formulation of information seeking and acquisition is used as presented in his general model of information behavior. Building on the work by Kuhlthau (1991) and Ellis (1989), the proposed model is believed to be useful in an effort to capture patients' active, as well as passive, search patterns.

RELATED RESEARCH

Several research studies have been performed focusing how Internet users seek out health information. For instance, Eysenbach & Köhler (2002) studied the methods used by health consumers to search the Internet for medical information and how the information is appraised. The study was performed using a qualitative approach in a laboratory setting with focus groups and follow-up interviews. The authors conclude that, in spite of the rather inefficient search techniques, the participants were successful in finding online health information and that the use of search engines was the most common behavior to reach relevant web sites.

Mainly focusing on online information, Warner and Procaccino (2004) studied women's health information-seeking behavior. They address issues of why, where, and how women access health information and their awareness of different information sources. Using a survey method (119 respondents) the authors found women being active information seekers, mainly using search engines to access health-related Web sites. However, the study also showed low awareness among the participants about the sources as well as concerns about the reliability of the information found. Anigbogu and Rice (2001) provided an in-depth, over-time summary of one woman's progress toward learning how to use computers, the Internet, as well as health information Web sites to learn more about infertility, eventually leading to a more empowered relation with both her physician and husband.

Murero et al. (2001) studied Internet use among patients undergoing medical treatment. Using a semi-structured questionnaire, 82 telephone interviews were conducted with patients before and after cardiac surgery. Approximately 20% of the participants had experiences of retrieving online medical information; the study concluded that a main problem among these participants was interpreting and understanding the information found. The study also highlights the fact that some patients might avoid using the Internet for medical information. Referring to the field of social science and the work by Festinger (1957) on the theory of cognitive dissonance, the authors find that: "Avoidance of using the Internet to retrieve information related to medical diseases could be interpreted, in part, as an attempt by patients to defensively prevent anxiety, since, being highly involved with a problem, the patients tend to avoid other sources of stimuli that could generate further dissonance, anxiety, and stress" (p.4).

Some patients' deliberate avoidance of medical information is further developed in a study by Leydon et al. (2000) that captures important variations in

patients' information-seeking behavior (without specific focus on online information). Based on 17 in-depth interviews with cancer patients, the study found that, due to different coping strategies, patients have different needs for information during the development of their disease.

MODELS OF INFORMATION SEEKING BEHAVIOR

Several models have been presented focusing on various aspects of information-seeking behavior (cf. Napoli, 2001; Rice, McCreddie, & Chang, 2001; Wilson, 1999). For example, in the field of information science, Kuhlthau (1991) and Ellis (1989) illustrated the information-seeking process, which has influenced Wilson's (1997) formulation of his general model introduced in the next section.

Kuhlthau's (1991) stepwise model is based on theories and ideas of the user's cognitive processes. As an example, the stage of *initiation* is about the initial development of awareness about the existing problem and this phase is often characterized by feelings of uncertainty. This is followed by a phase of *selection* where the person, often optimistically, takes on the task to identify a general topic to investigate. The further investigation of that general topic is then pursued during the stage of *exploration*. Again, feelings of uncertainty increase as the person tries to extend his/her personal understanding of the topic. Kuhlthau (1991) described the next phase (*formulation*) as "the turning point of the ISP (Information Search Process) when feelings of uncertainty diminish and confidence increases" (p. 367). During the formulation phase the person goes to find a more specific subject that becomes the starting point for the stage of *collection* where relevant information related to that specific subject is gathered. Finally, *presentation* ends the search process and involves the task "to present or otherwise use the findings" (p. 368).

The model by Ellis (1989) is based on studies of information seeking preformed by social scientists. The model captures six characteristics or features of the seeking pattern: *starting* (activities characteristic of the initial search for information), *chaining* (follows chains of citations or other forms of referential connection between material), *browsing* (semi-directed searching in an area of potential interest), *differentiating* (using differences between sources as filters on the nature and quality of the material examined), *monitoring* (maintaining awareness of developments in a field through the monitoring of particular sources), and *extracting* (systematically working through a particular source to locate material of interest; Ellis, 1989, p. 178).

THEORETICAL APPROACH

With the objective to propose a *general* model of information behavior, Wilson (1997) brings together ideas from different models while also investigating a

variety of disciplines beside information science (such as psychology, consumer behavior, health communications studies, and information systems design). Such interdisciplinary approach to understanding information access and browsing have also been applied by Rice et al. (2001), and Murero et al. (2001), who combined communication science, cardiothoracic surgery, psychology, and sociology of consumption.

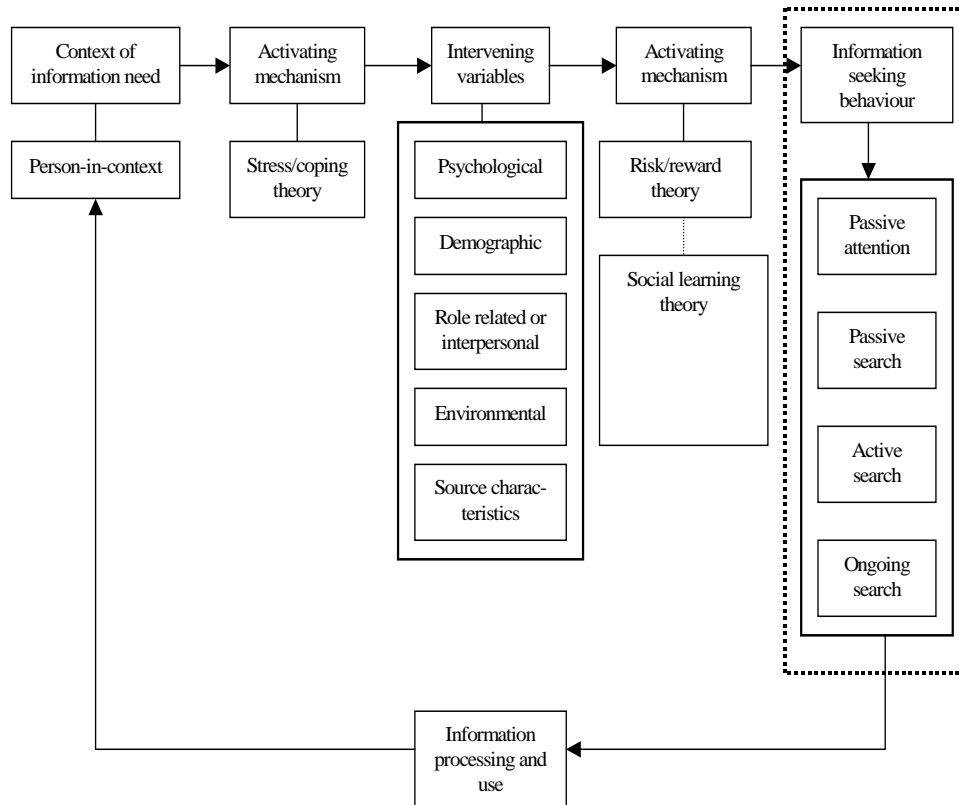


Figure 1. The general model of information behaviour (Wilson, 1997)

The present studies apply the features of Wilson’s (1997) general model covering information-seeking behavior (see Fig. 7.1). This part of the model is related to the ideas of Kuhlthau (1991) and Ellis (1989), as just presented, although Wilson added the passive modes of information “seeking”, sometimes also termed *acquisition*. The model is based on the idea that the information seeker has personal characteristics and is acting in a specific context of information need. The person is triggered by some activating mechanism to search for information on how to resolve the problem. Along the way there are various intervening variables affecting the person’s ability to search for information. Other activating mechanisms exist that help the person to overcome the barriers. The person then uses different search modes (*passive attention*, *passive search*, *active search*, and *ongoing search*) describing their information-seeking behavior. This is followed by a stage where the information found is processed and used.

The model illustrates four types of search modes (Wilson, 1997, p. 562):

- *Passive attention*: such as listening to the radio or watching television programs, where information acquisition may take place without intentional seeking;
- *Passive search*: signifies those occasions when one type of search (or other behavior) results in the acquisition of information that happens to be relevant to the individual;
- *Active search*: where an individual actively seeks out information; and
- *Ongoing search*: where active searching has already established the basic framework of knowledge, ideas, beliefs, or values, but where occasional continuing search is carried out to update or expand one's framework.

These modes serve as tools for presenting the empirical data of patients' search for online medical information. This means that the data is organized around various *features* of the search process in contrast to following the entire search process. Before presenting the empirical data, the overall research approach is outlined.

RESEARCH APPROACH

This research is based on semistructured interviews with patients active on the Internet. This means that the interviewees are using the Internet in various ways as means to cope with illness and their overall situation as a patient. During the interviews we went through issues of how they started to use computers and the Internet, their strategies for adopting Internet for medical information, and their experiences and ideas of the pros and cons of searching and using online medical information. The interviews were conducted as a conversation between the respondent and the interviewer. A few specified question areas were used to guide the performance of the interviews. The question areas served as means to ensure that all topics were covered, as well as to control the scope of the interviews, as contrasted with open-ended interviews (McCracken, 1988).

The researcher conducted a total of 18 interviews in two related studies. Each interview lasted for 40-75 minutes and was transcribed. The participants were guaranteed anonymity and the names used in the presentation of the data are fictitious. Also, since the interviews were conducted in Swedish, the quotes presented have been translated. To ensure that the overall meaning of each statement is captured and to avoid translation bias, the extracts has been discussed and double-checked with research colleagues.

The first study involved 10 patients sharing the experience of initiating and running patient-managed self-help groups on the Internet. The self-help groups offer a set of web pages containing a variety of medical information about a specific disease together with interactive facilities such as discussion boards and/or e-mail lists. The purpose of the self-help groups is mainly to provide

patients with medical information and the possibility to get contact with fellow patients for exchange of experiences on a peer-to-peer basis. The idea was to capture “patients in action” on the Internet, meaning that pattern of information seeking, as well as the interaction and communication performed, was central. Therefore, the selection of patients as initiators and managers of self-help groups was guided by the interactive facilities provided and the “patient activity” that occurred in the self-help groups. In addition, to get a broad patient perspective, the goal was to select patients representing several diseases and health conditions (involving multiple sclerosis, thyroid problems, whiplash injury, chronic prostatitis, fibromyalgia, endometriosis, polycystic ovary syndrome, panic disorder, and chronic fatigue syndrome/myalgic encephalomyelitis).

In order to provide a deeper example of how patients make their way on the Internet and search for online medical information, the second study focus on patients with a shared diagnosis. As a result, this study involved interviews with patients suffering from prostate cancer. Prostate cancer is cancer of the prostate gland. In Sweden, there are about 7,600 new cases each year. Slightly more than a third of all cancer in men is prostate cancer, which make this type of cancer the most common cancer among men. Prostate cancer mostly strikes elderly men, with more than two thirds of patients over 70 years old (Swedish Cancer Society, 2004). In United States prostate cancer is the second leading cause of cancer death in men – 230,900 new cases in 2004 - exceeded only by lung cancer (American Cancer Society, 2004). The incidence of this type of cancer makes these patients an important group to follow when it comes to Internet use and the specific needs and demands for online activities and medical information related to the diagnosis. Cooperating with the Department of Oncology at the Sahlgrenska University Hospital in Göteborg (Sweden), contacts with prostate cancer patients were established. During November 2003 to Mars 2004, eight (8) men were interviewed who had been diagnosed between 1995 and 2003. Three of the patients were recently diagnosed and treatment options were under investigation. Five of the men had undertaken various forms or combinations of treatments such as surgery, radiation therapy, and hormone therapy.

PATIENTS' ONLINE INFORMATION SEEKING BEHAVIOR

The patients provided rich descriptions of how they approach the Internet to search for information about their disease and overall situation as a patient. In order to capture this picture the results are presented using concepts from Wilson's (1997) general model as presented above. This provides the possibility to capture aspects of active as well as and passive search. Figure 2 illustrates the main scope of information seeking behavior identified among the patients in the two studies.

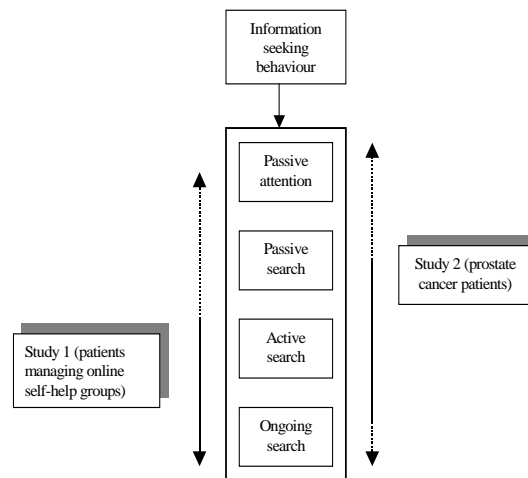


Figure 2. Main scope of information seeking behavior identified among the patients

Passive Attention

In Wilson's (1997) model, *passive attention* is when individuals accidentally get relevant and useful information. Although this does not represent active search efforts, these occasions are important to recognize as a part of patient's overall information-seeking behavior. Mary's story from her self-help group for women suffering from PCO (Polycystic Ovarie Syndrome) provides an example of the role of passive attention for patients' online information seeking:

"There were some articles published in Swedish newspapers that made people go out on the Internet and they found my web site and the number of members increased a lot during 1999 and even more in the year 2000 (...) There was an article in Aftonbladet (Swedish evening paper) in January (2003) and one in Expressen (Swedish evening paper) two weeks ago and I notice that at once. When there has been an article published my mailbox is full! As soon as newspapers draw attention to it (PCO) there are many patients contacting me."

Also, in the study, David, a prostate cancer (PC) patient, describes how he, besides his active search efforts online, has come across web addresses by coincidence by reading evening papers online: *"Aftonbladet [Swedish evening paper] has had some online articles that I have read and they end with 'read more here' and then I follow the links"*.

Passive Search

Passive search occur when relevant information is encountered unintentionally *during other search efforts*. In the studies, this is exemplified by patients being provided online resources by a third party, such as family, friends, healthcare providers/doctors or books and brochures, and so on. John, a PC patient, exemplifies such a passive search mode. He is familiar with the Internet and he reported regularly using online facilities. He has searched for information about PC in various sources, but when he was diagnosed, he did not turn to the Internet at once. Instead, his off-line search efforts provided him with information about online resources: *“In the beginning I didn’t search online. I bought a few books in English that gave me some input and after that I really started to search online”*. This differs from passive attention, as John was involved in actual search efforts as he encountered relevant information.

Further, passive search can be described as an additional way to find guidance to online resources in general. Among the participants, this is exemplified by Mark, a PC patient recently diagnosed and scheduled for surgery. He is familiar with computers from his office work, although he has limited experiences with the Internet. This reduces his search for online medical information, although he uses a few specific Web sites. Some of the web addresses were provided through a brochure about PC that Mark received during a visit at the doctor’s office. Other addresses he found in a book about PC written by a PC patient. However, he finds his abilities to reach online information beyond the given Web sites limited: *“I know that there is a lot to learn about PC out there (on the Internet) but I am not really sure where to go or how to search”*.

Similarly, Richard illustrates passive search as he describes how his online information seeking was limited to the Web sites provided in a leaflet about PC. At the time of the interview, Richard was discussing surgery as a possible treatment option: *“I didn’t search online instead it was through the leaflet that I found the information about these Web sites”*.

In the studies, patients report searching for information in Swedish, yet ending up on foreign (mostly English/American) Web sites where they encountered relevant information. As an example, for Charles, who organizes a self-help group for patients with chronic prostatitis, this has influenced the content on his web pages, as well as the number of international contacts he has today and the valuable information they have provided him with: *“I wouldn’t have had all this information if it wasn’t for these Internet contacts from all over the world”*. Also, the initiation of the self-help group was affected by contacts he accidentally made as he searched the Internet. Initially he *“happened to find an American newsgroup”* where he made contacts with other Swedish patients with whom he has cooperated in order to start the self-help group.

Active Search

The participants' use of *active search* mode is characterized by patients entering the Internet on their own looking for information and support triggered by an information void. Mary (cited earlier) pictures this as:

"When I was diagnosed I didn't get enough information from the doctors. At first I thought I was well informed but they (the doctors) were only talking about a small part of it all. So I was left to do some readings in books and I found almost nothing there. Then I went on the Internet and I discovered that there was so much I didn't know about this (PCO)".

A common method among the participating patients for entering the Internet was to perform broad searches using search engines. This strategy takes patients to a variety of Web sites and put demands on the patient's ability to choose among the hits and to judge the information found. Tom (PC patient), being a frequent Internet user and familiar with information-seeking procedures online, describes how he first entered the Internet looking for medical information about PC:

"Well, I used a search engine and went for 'prostate cancer' and then I made my way from one site to the other following links back and forth".

On the question of how he chose between the many hits that were generated, he replied:

"I believe it was randomly. I clicked until I found something that seemed reasonable and then I followed the links from that."

When asked about what made him decide what could be considered "reasonable", he described this as an effort of trust-building mainly on his personal references about credibility: "...there must be knowledge represented and hospitals and doctors behind – not just private individuals who believe they have the solution to everything." As a complementary strategy to judge online information, Tom also compares the sources with each other. He explains:

"I compare the information from various sources...if you do that the picture will get more balanced. Perhaps you will never get the whole truth but at least you will get rid of the more extreme forms of medical advices".

In addition, active search mode can be described as an exhaustive way of exploring the Internet for medical information. One example from the first study is Maria. She is a sufferer of multiple sclerosis (MS) and an organizer of an online self-help group for patients with MS. She describes her initial search

behavior as: “I wanted to find out as much as I could...I read everything online...everything there was to know about MS.”

Similarly, Eric (PC patient) searched extensively online as he realized that there was a lot more to know about prostate cancer than he first expected and that he himself had to find that out: “It was after the surgery that I realized that there was so much that I was not informed about. One evening I decided to start (to search online) and when you start you find so much...so many threads you just have to follow”.

Ongoing search

According to Wilson (1997), active search might grow into an *ongoing search* mode where the individual uses, tests, and elaborates a personal frame of reference including knowledge, experiences, and viewpoints derived from earlier search efforts. Consequently, the individual uses the results of previous information seeking but occasionally makes new searches to further develop the frame of reference. An example of ongoing search is the use of “favorites” which are Web sites that the users keep returning to, so are kept and listed in the user’s Internet browsers for easy access. In the studies, such Web sites were regarded as trustworthy, relevant, and updated. For example, David (PC patient) often returns to the “state-of-the-art” page about prostate cancer produced by the Swedish National Board of Health and Welfare:

“I went to the page for the “State-of-the-art” in an early stage and I have read those papers at least 10-15 times. Maybe it has become my “bible” so to speak”.

Another example of ongoing search and the use of favorite Web sites is provided by Sara, a thyroid patient running an online self-help group and a Web site with extensive information about thyroid problems. In the work with her disease and the self-help group, she has often returned to an American web site about thyroid that has become a model both for her self and for many of the members of her group:

“Thyroid.about.com is an American web site about thyroid and...well, there is so much information! It was started by a patient who wrote a book some years ago about thyroid problems. At first the web site was quite limited but now it has grown and presents huge amount of information. We have discussed that perhaps our group should now become a Swedish corresponding Web site...and many members want that too.”

Further, participation in online discussions with fellow patients is an additional form of ongoing search providing the opportunity for patients to further develop and test their knowledge and personal frame of reference. Irene,

who is managing a self-help group for patients with endometriosis, provides her thoughts on such interchanges:

“...all the girls on the mailing list have something to give. They have knowledge and experiences and they have been through things or taken certain medications...it spreads to others and they give back...everything they have been through can be used for good things.”

DISCUSSION

The participating patients applied a variety of online search modes where some modes might be considered more beneficial than others. However, when carefully considering the consequences of the online information seeking behavior, numerous aspects should be taken into account revealing a complexity that cannot easily be reduced to the dichotomy of pros and cons (Morahan-Martin, 2004; Warner & Procaccino, 2004). Recognizing this multifaceted picture, the following discussion aims to give voice to patients themselves. Firstly, the discussion will be centered on three themes: accessing online medical information, social support, and information accuracy and applicability. The themes summarize important consequences of the participants' online information-seeking behavior. Secondly, the discussion considers three balancing factors deriving from the interviews also: coping strategy, resource requirements, and online information-seeking assistance. These factors capture circumstances important to consider in order to deepen and nuance the picture of the participants' online information-seeking behavior. To support the discussion, Fig 3 summarizes the search modes, identified themes, consequences and balancing factors.

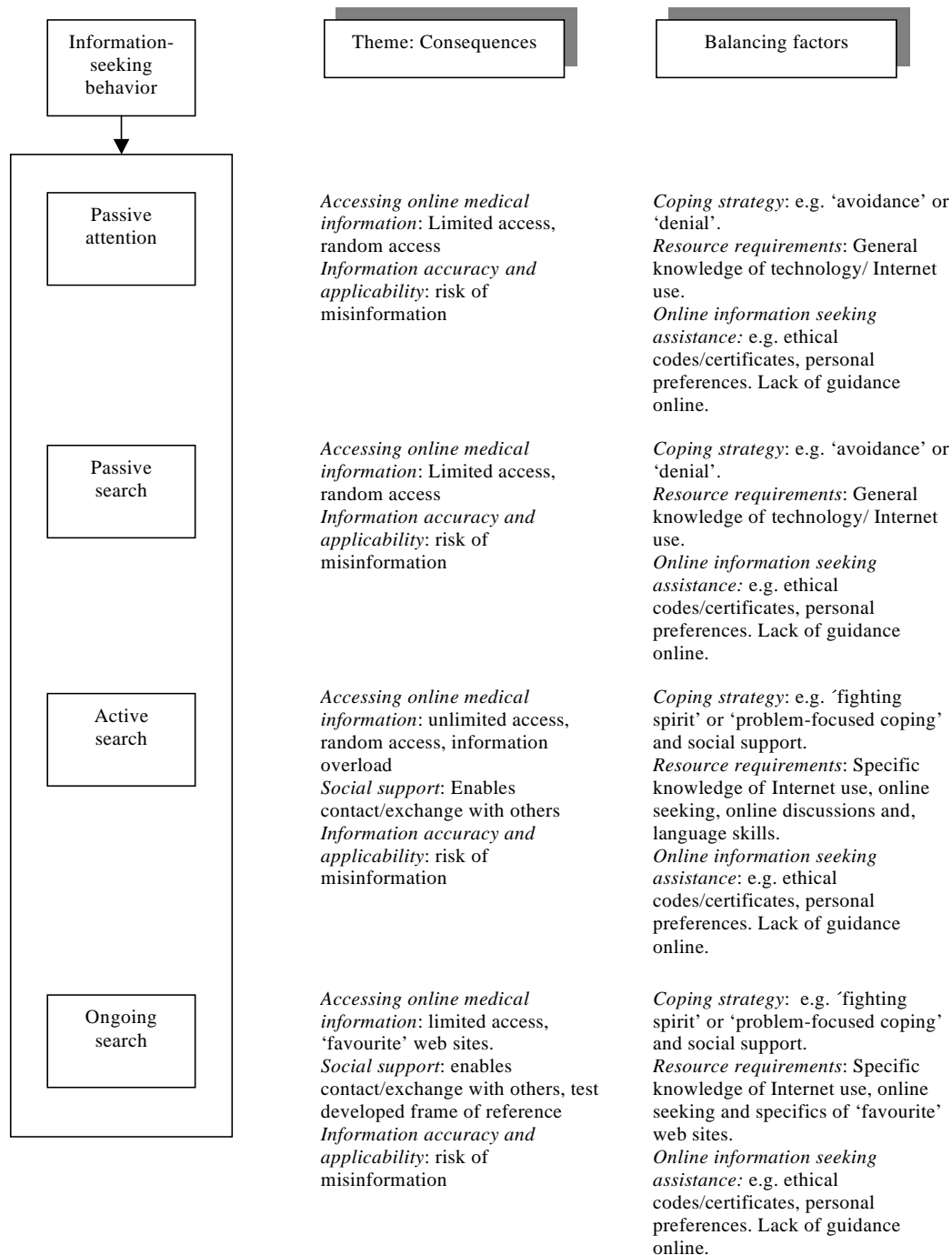


Figure 3. Summary of the search modes, identified themes, consequences and balancing factors.

Accessing online medical information

Wilson (1997) included passive search modes as a part of individuals' information-seeking behavior as an attempt to illustrate that "other modes of 'searching' do take place" (s. 562) adding to ideas of information seeking as solely active (see also Rice et al., 2001). The participating patients' use of passive attention and passive search naturally generate a limited and random set of

medical information. Usually the consequences of limited access to medical information online are viewed against issues of computer literacy and general knowledge of Internet use (Morahan-Martin, 2004). As we discuss in the following paragraphs, patients' need for such competencies is undoubtedly essential to their online information-seeking behavior. However, the passive search modes that limit the amount of information obtained should also be considered in relation to the fact that some patients do not *want* additional information (Henwood et al., 2003; Murero et al., 2001).

Although there might be several reasons for patients to limit their information seeking, this is fruitful to consider from the perspective of coping strategies (Johnson, 1997; Wilson, 1997) as a balancing factor. Applying a well cited definition, coping is "...*the persons' constantly changing cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the person's resources*" (Lazarus & Folkman, 1984, p. 141).

Facing illness is an example of a stressful (external and/or internal) demanding situation characterized by high level of uncertainty (Johnson, 1997). Various strategies to deal with such situations have been identified (cf. Festinger, 1957; Lazarus & Folkman, 1984). For instance, some patients' reluctance to seek additional information could be explained as a coping strategy characterized by avoidance (Lazarus & Folkman, 1984) or denial (Sullivan & Reardon, 1986). In the study Ian (a PC patient) illustrates such avoiding strategy as he expresses: "*I am not really sure if I want to find anything more on this (prostate cancer)...it shouldn't get too much*".

Limited access to online information is a consequence of ongoing search as well. For instance, applying this search mode, participants in the studies limited their search to web pages that could be described as their "favorites". Such limitation of the information seeking is, however, a result of earlier active search efforts where the person has developed a clear focus and is able to perform targeted information searches (Ellis, 1989; Kuhlthau, 1991). However, returning to the resource requirements as an important balancing factor, patients need competencies such as how to manage the Internet and online information-seeking procedures in order to develop this mature way of online seeking (Henwood et al., 2003). In addition, patients must be able to handle the specifics of their favorite Web site, such as search methods in certain databases or a how to participate in discussion boards, and so on.

As a contrast to limited search efforts, the active search mode results in considerable and almost unlimited amount of information (cf. Eysenbach & Jadad, 2001; Hardey, 1999; Morahan-Martin, 2004). However, a broad and extensive way of approaching the Internet creates advantages as well as less desirable consequences. On the hand, this means a possibility to access a variety of information sources such as medical databases and journals as well as web pages of patient associations, health portals, cyber doctors, and so on, providing patients the opportunity to get additional information and different views of

their problems. On the other hand, the access of such vast amount of medical information increases the risk of “information overload” (Reeves, 2000), causing patients to experience confusion, frustration and disempowerment (Henwood et al., 2002). In the study Steve, a PC patient, offered a comment on information overload that illustrates the view of several of the participants: *“You can’t read everything. It is hopeless since there is so much. You have to sort out what to read and that is difficult”*.

Additionally, active search can be considered from the perspective of coping strategies as a balancing factor. For instance, contrasting avoidance or denial is what Sullivan and Reardon (1986) called “Fighting spirit”. This coping strategy is characterized by highly optimistic attitudes, active search for information, desire to know as much as possible, and low levels of distress (Johnson, 1997, p. 116). Similarly, Lazarus & Folkman (1984) term such behavior *problem-focused coping*. This way of coping was highlighted in the studies as several of the interviewees described their active search efforts online as a form of therapy. David (PC patient) illustrates this as he describes: *“I felt good being on the Internet. There was so much. I could surf, search and go through stuff and print it out. I copied things to my own computer so I had several hundred pages about prostate cancer.”*

The consequences of active search are thus both positive and negative. In order to deal with the problems and to make the most of the good parts, the requirements for particular resources as a balancing factor become important once more: here, with an emphasis on language skills and knowledge about information seeking. In the second study Tom, a PC patient describes some of the barriers for active online information seeking: *“The first thing is language skills. You have to now English...well, first you have to know how to handle a computer and how to use the Internet but then you really must have language skills in order to access Web sites other than Swedish”*.

Social support

The active search mode brings not only medical facts but also an increased opportunity for patients to find their way to online spaces (such as discussion boards, e-mail lists, and/or self-help groups) for contact with fellow patients for support and empathy. (Ferguson, 2002; Preece & Ghazati, 2001). Ongoing search provides the opportunity for this support on a peer-to-peer basis, also. For instance, through revisits to favorite Web sites providing such interactions patients are able to test and further develop their knowledge or personal frame of references developed through previous information seeking (Preece, 2000).

The usefulness of this type of contact with fellow patients has been pointed out (cf. Ferguson, 2002; Josefsson, 2005; Rice & Katz, 2001). In the performed study, Mary (managing a self-help group for women with PCO) gives a good example of this:

“The best thing is that I have got in contact with so many other women. We have exchanged many common experiences and this has really meant a lot to me. And I feel that I know so much more from the things I have learned from others. We have shared our experiences and when I go to see my doctor I know my rights in a completely new way. The contact with others in the same situation have made me stronger and helped me put new demands on my healthcare provider that I probably wouldn’t have done otherwise”.

Additionally, Mary’s statement illustrates the two-sided benefit of patient-to-patient support, meaning that the activities offer patients an opportunity to receive as well as *provide* social support. This is captured also in a study by Reeves (2000) on HIV-positive individuals where the coping effects of online support were emphasized as concerning both the possibility to get help, but just as much as an opportunity to be able to help others.

Further, it should be noted that online interactive forums provide patients the possibility to seek information in an indirect way. This so called “lurking” (Nonnecke & Preece, 2001), where individuals follow online discussions without posting or commenting their own comments, is an additional strategy to find other’s stories, knowledge, and experiences. Among the participants this is well-known and Linda (running a self-help group online for patients with panic disorders) expresses this as:

“Some simply want to read. On the page ‘Others’ stories’, they can read about this (panic disorders) happening to other people as well. It is very comforting since you feel as the loneliest person in the world and you think that ‘this happens only to me”.

To deepen our understanding and to balance the picture of patients search for contact with others, ideas of coping are once again believed to be helpful. In the coping literature, the seeking of social support is a well-known strategy to meet the challenges of facing illness (cf. Lazarus & Folkman, 1984; Reeves, 2000; Sullivan & Reardon, 1986). Social support involves several forms of support beneficial for the patient. For instance, referring to the work by Schaefer, Coyne, and Lazarus (1982), Lazarus & Folkman (1984, p. 250) described the seeking of social support as including “informational” support (like providing information or advice and feedback) as well as “tangible” (involving direct forms of aid) and “emotional” support (including attachment and reassurance). These forms of support are also illustrated in Mary’s statement just discussed.

To further balance the picture, it is necessary to again consider the specific resources and qualifications required in order to participate and benefit from social and human supportive activities online (Henwood et al., 2002). Besides the earlier mentioned skills on language, Internet use, and information management,

patients also require proficiency in how to (technically and socially) act in discussion boards or on e-mail lists (Preece, 2000).

Information accuracy and applicability

The third theme is connected to all four search modes and involves issues of information accuracy and applicability and the risk of becoming misinformed when pursuing online seeking for medical information. The risk concerns medical facts (Eysenbach & Jadad, 2001), as well as the information obtained through online personal support (Ferguson, 2002). In addition, problems of becoming misinformed include the risk of misinterpreting otherwise correct medical information and difficulties of judging the usefulness of the information in relation to the personal case of illness (Klein-Fedyshin, 2002). An example of this is patients entering Web sites directed towards healthcare professionals. John, suffering from prostate cancer, illustrated this as he refers to the difficulty of accessing “doctors’ Web sites where the information is on a deeper medical level and since I’m not a doctor I quickly lose track of what I read”.

The issues of online information accuracy and applicability are often viewed against the background of patients’ individual abilities of assessing the information. Currently, high demands are put on patients to accomplish the task and to further develop their competencies (Eysenbach & Jadad, 2001). This means that besides the technical and social skills discussed earlier, patients must further develop their knowledge concerning information uncertainty. This is highlighted by Henwood et al. (2002) as the authors emphasized the “*need for information literacy skills to be developed more widely so that the public are able to be aware of the relevance of information sources, to ask critical questions about information they access and to make judgments about the validity and quality of the information accessed*” (pp. 88-89).

As a balancing factor, issues of online information accuracy and applicability should also be discussed in the light of online information seeking assistance supporting information assessment. So far, much of this work has involved the use of online certificates or ethical codes (Adams & Berg, 2004) as instruments to find reliable online information. Other forms of guidance have, hitherto, been rare, leaving online medical information seekers to rely on their personal preferences about how to judge the information (Eysenbach & Köhler, 2002). However, recently several studies have emphasized the need for more direct forms of guidance on the Internet to reliable and relevant information sources (cf. Morahan-Martin, 2004; Murero et al., 2001; Salo, Perez, Lavery, Malankar, Borenstein, et al., 2004; Seidman, chap. 10, this volume). Also, these studies call for an increased responsibility and participation by healthcare providers to support this development. The patients in the reported studies confirm the lack of online guidance as they have been more or less left on their own, without support from healthcare to find trustworthy and timely online information. For

instance, none of the participating patients had *directly* been advised about online sources for additional information by their doctor or healthcare provider (see also Rice & Katz, chap. 8, this volume).

LIMITATIONS AND FUTURE WORK

This chapter is an initial attempt to take a broad perspective on patients' information-seeking behavior. By means of the participants' experiences, the analysis has focused on a number of opportunities and challenges associated with patients' online information seeking. The features of information-seeking behavior employed from Wilson's (1997) general model has well served its illustrative purpose and supported the idea to capture actual search patterns. However, to illuminate further complexities such as patients' *shift* between and/or their *mix* of different search modes, the model requires some modification as well. Such development would enhance the utility of the model, although this calls for additional exploration of patients' online information behavior on issues like frequency of online information seeking and development over time.

In addition, the analysis provided briefly reviews a number of dimensions of patients' online information-seeking behavior; but each should be explored in greater detail. For instance, the studies only touch on patient characteristics influencing their search behavior, although issues of education, income, sex, type of diagnosis, and so on, are important factors that should be considered profoundly in future work.

Finally, the studies use a qualitative approach and are based on a limited number of interviews and self-reported experiences of information seeking online. In order to get a more comprehensive picture future work should acknowledge the use of quantitative approaches as well.

CONCLUSIONS

Informed by ideas from information science, this chapter illustrates patients' different ways of seeking online information. The research findings discussed here give voice to patients' experiences and deriving from the empirical data the analysis focus on three themes related to consequences of the observed search behavior: accessing online medical information, social support, and issues of information accuracy and applicability. In order to provide a nuanced picture, the findings further suggest that the search mode applied and the amount and type of information obtained should be viewed against the background of balancing factors. Stemming from the participants' experiences the balancing factors considered here are related to patients' coping strategies, resource requirements, and online information seeking assistance available.

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PATIENTS' INITIATION OF SELF-HELP GROUPS ON THE INTERNET: A COPING PERSPECTIVE

Ulrika Josefsson

Abstract

This article addresses chronically ill patients' initiation of online self-help groups in Sweden. Drawing on ideas from coping theory the initiation is explored and understood in terms of individual coping strategies. Using a qualitative approach involving observations of 15 self-help groups and 10 interviews with initiators, the article identifies the coping strategies of: information seeking, the search for social support, and to facilitate fellow patients. The article provides a deepened picture of the strategies along with an outline of the contributions of the coping perspective. The article argues that focusing on initiation by means of coping increase our understanding about individual driving forces of this form of Internet use. In particular, coping elucidate the role of individual needs related to coping processes when initiating the self-help groups. In addition, this focus on patients' initiation of online self-help groups is believed to support the identification of patient-centric requirements for further development of Internet use in the patient-healthcare relationship.

INTRODUCTION

This article addresses chronically ill patients' initiation of self-help groups on the Internet. These are online groups started and managed by patients and provide information and communication on a peer-to-peer basis. Typically the web pages of the group contain extensive information about a certain health condition and provide interactive facilities like bulletin boards, e-mail lists, and/or chats for patient-to-patient communication. The information available involves medical

facts as well as practical information about how to manage everyday life living with illness.

Lately this particular online phenomenon has received increased attention (c.f Demiris, 2006; Johnson & Ambrose, 2006; Maloney-Krichmar & Preece, 2005; Murero & Rice, 2006). This relates to online self-help groups as a significant example of how individuals make use of information technology to support their management of difficult life situations. In addition, the groups constitute an interesting and highly relevant online resource for healthcare practice to learn and benefit from when developing Internet use in the patient-healthcare relationship (Johnson & Ambrose, 2006; Demiris, 2006).

In previous research Preece (1999) focus on empathy as a *social phenomenon* of these groups. By means of a content analysis of 500 messages from the archive of a patient managed bulletin board, Preece introduced the idea of “emphatic communities”. The conclusions emphasize the need for a technology development that manages to balance patients’ need for empathic and factual communication. Maloney-Krichmar & Preece (2005) continue this work by providing a rich picture of *the social dynamics* of a self-help group. The work reports from a 2½-year ethnographic study involving observations, text analysis of bulletin board messages and interviews with group members. The study resulted in a number of factors to support future development of online groups such as the need for a 24/7 form of accessibility, technical support for formation of subgroups, development of group norms, moderator role, and the need for guidance to reliable information sources online. Further, Josefsson (2005) provide complementary work on the *social and technical structure* of patients’ self-help groups. Applying a qualitative multi-method approach the study conclude that the groups contain features that support patients’ coping processes such as the provision of specific medical information for health education as well as spaces for social support providing the possibility to receive support as well as to help others. In addition, Lester et al (2004) focus on the *technical instruments* applied in a study of patients’ actual forming of self-help online. In their work with the Brain Talk Communities (www.braintalk.org) the authors studied patients’ organizing of self-help tools. The tools mainly consist of discussion boards and the authors conclude that by studying patients’ forming and managing the support contribute to an increased knowledge about the complicated structure of how patients reach out and connect with others. Finally, Josefsson & Ranerup (2003) discuss these groups as an example of emergent forms of Internet use *influencing the relationship between citizens and public sector services*. Here, the authors conclude that the self-help groups are sophisticated instruments in a learning process that supports the citizens’ development into active consumers of public services.

However, previous work mainly focuses on aspects of participation in patients’ self-help groups and group structure as well as the role of the groups in relation to healthcare service. Together this contributes to the overall

understanding of the groups as online phenomenon and in a wider perspective to the improvement of this form of IT support. However, a less studied aspect that would further complement the picture concerns *why* some patients take on the work to start and manage these groups. Consequently, from a patient perspective this article addresses the *initiation* of patients' self-help groups on the Internet. The main objective is to explore individual driving forces involved when initiating self-help online. It is argued here that a focus on these aspects of initiation contributes with increased knowledge of patients' needs and requirements when facing illness. This is believed to support our understanding of the patients as users of information technology and in a wider perspective support the development of IT use in the patient–healthcare relationship (Demiris, 2006; Johnson & Ambrose, 2006; Van't Riet et al., 2001; Wilson, 2003).

With a research approach aiming to get close to the patient perspective and the underlying processes of initiating the self-help groups the article draws on the ideas of *coping theory* (Lazarus & Folkman, 1984, Folkman & Moskowitz, 2004, Snyder, 1999). This theoretical approach is widely used in individual psychology to understand and explain the behaviours of individuals facing stressful life events (like facing chronic illness). Here, it is argued that a coping perspective further deepen our knowledge of the groups as it provides a possibility to grasp human behavioural processes from the perspective of the ill person. In addition, a coping perspective provides the possibility to capture patients' needs and requirements of Internet use in illness situations in more specific terms. A second objective of the paper is therefore to introduce coping as a tool for exploring IT use.

For the investigation of patients' initiation of online self-help groups a qualitative approach is employed. By means of observations of 15 self-help groups and 10 semi-structured interviews with initiators the work reported illustrates patients' actual experiences. The aim is to provide an empirical *example* rather than to generalize from the findings. Further, the study reports from patients' initiation of self-help groups in Sweden. This contributes with an example of Internet use in a country with high level of Internet access among the public but with limited tradition of self-help (Kummervold et al. 2002). Further, it is an example of Internet use when facing illness in non-English countries.

The article is structured as follows: First, there is a section about the employed research approach followed by an outline of coping theory. Thereafter follows the results of the performed study focusing patients' actual coping online. Finally, there is a discussion aiming to deepen the picture of patients' initiation of online self-help by means of the coping perspective.

RESEARCH APPROACH

The Swedish online self-help groups studied in this article contain web pages initiated and run by individuals suffering from a chronic illness or injury. In efforts to manage their health situation, they have found the information about their disease, off-line and online, inadequate since it is not always available in their own language or presented in a way easily accessible also to the laymen. After searching and bringing together information about the disease they have presented it on a web page. To get in touch with fellow sufferers they have gradually added functions such as e-mail lists, discussion boards, guest books and/or chats. Some patients initiated their self-help group by first starting an e-mail list and subsequently develop the web pages.

Two related studies (performed in 2001 and 2002) provide the empirical basis of this article (see Table 1).

Method	Self-help groups	Question areas
Observations	15 Swedish patient managed self-help groups. Health conditions covered: <i>Breast Cancer, Prostate Cancer, Whiplash injury/ Polycystic Ovarian Syndrome (PCO)/ Endometriosis/ Multiple sclerosis (MS) / Chronic Fatigue Syndrome / Chronic prostatitis/ Fibromyalgia/ Panic disorder/ Thyroid disease</i>	Structural design/ performed practices/ what the self-help groups offer visitors or members in terms of interaction and information.
Semi-structured interviews	10 interviews with initiators of 10 self-help groups involving the following health conditions: <i>Whiplash injury/ Polycystic Ovarian Syndrome (PCO)/ Endometriosis/ Multiple sclerosis (MS) / Chronic Fatigue Syndrome / Chronic prostatitis/ Fibromyalgia/ Panic disorder/ Thyroid disease</i>	Why and how the self-help groups were started/ how they have developed/ pros and cons of initiating and managing an online self-help group.

Table 1. The two related studies of Swedish online self-help groups.

The first study involved *observations* of self-help groups on the Internet. The idea was to examine such groups initiated and managed by individuals addressing a special disease or patient group providing interactive facilities. These aspects guided the selection of self-help groups. By the use of Internet search engines like “AltaVista”, “Google” and “Yahoo” 15 online self-help groups were selected representing various health conditions (some health conditions were represented by two online self-help groups) (Table 1). The participating self-help groups had been online between two and seven years. The observations resulted in an initial understanding of the structures and design of the online phenomenon and the performed practices.

The second study involved *semi-structured interviews* with the initiators of the previously observed self-help groups. Ten of them agreed to participate. Seven of the interviewees were women and three were men. Their ages varied between 25 and 65. The interviews were guided by a semi-structured approach involving only a few specified question areas and were performed as a conversation between the researcher and the interviewee. The question areas involved issues on how and why the groups were initiated and how they have developed since the start. The questions also concerned opportunities and challenges related to the initiation of the groups. Each interview lasted for about 45 to 70 minutes and were tape-recorded and transcribed. The participants were guaranteed anonymity and the names used in the presentation of the data are fictitious. In addition, in Sweden the development of online self-help groups are still in its infancy although emerging. This means that the number of groups is still limited especially in comparison with Anglo-American countries. Therefore, to further protect the identity of the interviewees the author has decided not to reveal the names of the self-help groups or their web addresses.

The collected data was analysed using an inductive process where the material has been read and reread searching for patterns and features (Hammersley & Atkinson, 1995). Two main stages describe the iterative process. The first stage involved the identification of general patterns and features running through the data. The second stage involved sifting out additional patterns and features on gradually more specific levels. This included both anticipated issues such as view on the process of initiating online self-help groups, and emergent issues such as the participants’ specific ideas of online information and communication. More particular, the analysis focused on regularities of the empirical data as well as on a further analysis of deviant cases in an effort to balance the characterizations (Silverman, 2005). Further, the process of analysis involved the seeking of patterns within each performed study as well as across the studies. Also, the analysis was guided by the principal aim to provide significant *examples* of the phenomena rather than to quantify and to generalize from the collected material.

COPING THEORY

Coping is about how humans deal with stress related to difficult and unusual life events. It is concerned with our responses, from a practical, physical, emotional, and psychological point of view (Snyder, 1999). The concept of coping is used in several disciplines covering numerous problem domains (c.f. Lazarus & Folkman, 1984; Folkman & Moskowitz, 2004; Snyder, 1999). Over time, this has resulted in a variety of definitions (Sullivan & Reardon, 1986). However, Lazarus & Folkman (1984) presents a well-known definition that suits the purpose of this paper: “*We define coping as constantly changing cognitive and behavioural efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person*” (p. 141). In addition, White (1985) provides a simplification illustrating the characteristics of the situation when referring to coping: “*coping refers to adaptation under relatively difficult conditions*” (p. 123).

Historically the concept of coping has developed along two major paths. The first, concerns influences from psychoanalytical theory and the field of ego-psychology (Snyder, 1999). In this field defence mechanisms constitute an important basis for the discussion on individuals’ adaptation to difficult life events. The primary focus is on enduring “traits” or personality deciding the coping behaviour. This view relates to coping as a typically stable and unchangeable way of dealing with difficulties regardless of the situation.

Cognitive psychology and the research on stress influenced the second path. Early research in this field concerned the human biochemical response scheme ('fight or flight' responses) when exposed to stress. However, these ideas were abandoned by sociologist Richard S. Lazarus and colleagues who were first to move the focus towards active appraisal processes leaving behind earlier ideas of traits (Lazarus, 1966; Lazarus & Folkman, 1984). Instead, Lazarus’s ideas of coping involved a transactional model focusing on the interaction between the individual’s cognitive appraisals and the environment.

Contrasting the ideas of traits as automated ways of coping (Snyder, 1999) this conceptualization involves *a process-oriented and context dependent view of coping* affected by the development of the situation and the person’s reappraisal (Lazarus & Folkman, 1984). This refers to the following general process: when exposed to stress an individual makes a first primary appraisal of the situation. If the situation is perceived as a potential threat, a secondary appraisal is made when the person investigates the resources available to deal with the threat (or stressor). The efforts to cope with the situation are followed by the stage of re-appraisal. The individual then evaluates the results of the coping behaviour in order to decide whether a threat is still present and if additional coping activities are needed.

Dealing with the stressful situations individuals combine coping strategies in performing different coping activities. Lazarus & Folkman (1984) identified two major functions of the coping strategies: 1) *emotion-focused coping*, referring to activities aiming to regulate the emotions and the perception of the situation: 2)

problem-focused coping, directed towards the management of the problem and specific aspects of the environment that is causing the distress.

The coping process as context dependent means coping should be viewed in relation to the demands of the particular situation (Folkman & Moskowitz, 2004; White, 1985). More specific, this includes both internal personal and psychological aspects as well as external features of the environment (Aldwin, 1994; Maes et al., 1996). However, context dependency also relates to the mutual influence between the context and the coping activities. This refers to the recognition of coping as part of social and cultural structures (Aldwin, 1994) affecting coping behaviour and equally being affected by the activities performed. This mirrors an idea of individuals as co-creators of their environment where “/.../*coping involves changing the environment as well as oneself*” (Lazarus & Folkman, 1984, p. 233).

PATIENTS' COPING ONLINE

In the study the participants provided a picture of the initiation of the groups as not deliberate but more related to their own management of the illness situation. The following seeks to illuminate this dimension of the initiation and the quotes illustrate the patients' activities and perceived needs related to the onset of their illness. Thus, the activities and needs are viewed as an expression of the patients' coping process when managing the situation of facing illness influencing the patients to initiate their self-help group.

Information seeking

After being diagnosed with a chronic illness or injury the patients in the study reported of how the initial feelings of pain, fear and agony were accompanied by a growing need for information about the disease. The participants expressed this as “*a need to know everything*” or as “*a need to read it all*”. They perceived the information provided by their treating clinic or physician as too limited. This was pointed out by one of the patients:

“...*the information I got from the doctors was insufficient. First I thought it was okay but then I realized that they [the doctors] were talking about a limited part of it all...then I realized there was so much I didn't know...then I started to search the Internet...*” (Rita, ‘Polycystic Ovary Syndrome’, PCO)

The participants described *the search for information* as a kind of “*self-therapy*” coping with a difficult life situation. They described how it made them feel stronger to take action and to do something about their situation. Ann, suffering from multiple sclerosis illustrated this saying: “*I believe it [the information seeking] was my way of getting a grip of what I had to deal with*”.

The search for medical information involved various sources online as well as offline, both national and international. The sources used were newspapers, books, medical journals, online databases, health portals on the Internet and, private homepages, etc. Several of the interviewed patients expressed this as: *“I read anything I could possibly get my hands on...”*

Observing the web pages of the self-help groups makes the interest in all sorts of information related to the disease obvious. The content and structure of the pages show the results of extensive search efforts aiming to map out various features of the diseases. The participants describe how their interest first concerned information on a general level, involving basic facts about the disease such as symptoms and treatments. The information seeking then turned towards specific issues of the disease like news from the medical research field and information that they could relate to their own personal case of illness. This is illustrated by Catherine (thyroid problems):

“When you have been around for a while there are questions coming up such as how to make sense of your test results or what particular symptoms means just for your case. You already know a lot but you want to find out about things that even your doctor doesn’t know, like the meaning of research reports and so on.”

In addition, the handling of the information found seemed to be an important part of dealing with the overall situation. Linda who is running a self-help group for people with panic disorder captures the process of bringing together the results of the searches for information:

“First I searched for a lot of information...and that was good...then I tried to structure it all...for me. That’s the way it started...I tried to make sense of it by organizing the information...when I did that it turned out an entire web site.”

Social support

For the study participants the process of initiating online self-help groups also involved a coping strategy related to *search for social support*. In some cases, this search was direct as the self-help group was started as an e-mail list. Susan, a leader of a self-help group for women with endometriosis provides an example:

“I tried to get contact with a patient association ...I really needed someone to talk to. Unfortunately, there was no association active at the time...so I started the e-mail list...that’s how it all began. A lot of girls joined just a few days later...then I could finally talk to others. It was great to feel that I was not alone and that others had been through exactly the same thing.”

Other patients started by setting up a web page about the disease (and developed the interactive facilities later) and reported that the contact with fellow patients became more important after they had received some feedback on their web site from others. This indicates that for some patients the search for contact became important later in the process of initiating the self-help group. In the study this is illustrated by Rita (previously mentioned) who is running a self-help group for women suffering from PCO. Below she describes her initiation of the group:

“The reason to start the web page was basically to put together all the information that I had collected on the Internet. I never realized that a lot of people would start to contact me. The first time I got an e-mail I was really surprised!”

However, later in the interview Rita is asked about the main personal benefits of initiating her self-help group. Her answer shows the growing importance of the social support:

“The best thing is that I have got contact with so many other women. We have exchanged many common experiences, this has really meant a lot to me and I feel that I know so much more from the things I have learned from others. We have shared our experiences and when I go to see my doctor, I know my rights in a completely new way. The contact with others in the same situation have made me stronger and helped me put new demands on my healthcare provider that I probably wouldn’t have otherwise”.

In addition, Mary (fibromyalgia) agrees on social support as a critical factor when the self-help groups are initiated:

“I think it is a really good thing that you get contact with others. That’s what it’s all about, in a way. That’s the driving force behind all this...to get contact with others suffering from fibromyalgia.”

Facilitating others

The coping strategy to seek social support during the initiation of the self-help groups was coexisting with the desire to *facilitate others*. The participants provided examples of how this altruistic behaviour served as major driving force behind the self-help groups and helped them to cope with their disease.

“I think I have learned quite a lot about this [whiplash injury] so I wanted to try to help others as well...I know how bad you feel and this [an e-mail list] is a good way to facilitate others.” (Lisa, whiplash injured)

“ . . . it makes me happy to be able to help others. For me . . . I am past the worst . . . but I know how hard it was and every time I get an e-mail from someone who thanks me it is most rewarding . . . it is a very satisfying feeling.” (Ann, multiple sclerosis)

“My aim is not just to provide facts but also...even more important...they should get response from someone who understands the hell they often are going through...If I can manage to get them, just a little bit out of that situation of powerlessness – then I have achieved a lot and that is very important to me.” (Ian, whiplash injured)

In addition, text on some of the web pages of the self-help group mirrors this desire to facilitate others. Below is an extract from a self-help group for people with panic disorder:

“I had no idea about what was happening to me, and it made me even more afraid that nobody could give me straight answers about it. This is my reason for creating this site for everyone with panic disorder symptoms, because I believe in information and knowledge as an important part in the treatment.”

A COPING PERSPECTIVE

In the study three coping strategies appeared as particularly important when the participants started their self-help groups: *information seeking*, *social support* and *facilitating others*. The following aims to deepen the picture of these strategies and their role in the process of initiation. However, it should be noted that the identified strategies do not represent the participants' *entire* coping process and/or strategies applied. Other forms of coping (like denial, escape, avoidance, wishful thinking, and so on) might have occurred as well. The second part of the discussion introduces the contributions of a coping perspective on patients' initiation of self-help online. Some of the limitations and future research challenges close the section.

Coping strategies in the patients' initiation of the online self-help groups

Dealing with their diseases and overall patient situation the participants share the behaviour to perform extensive online *information seeking*. They search for relevant information serving as a ground for further actions (White, 1985). If we consider this form of behaviour in terms of coping this strategy signals a “*fighting spirit*” recognized by “*highly optimistic attitude*” and “*search for greater information*” (Sullivan &

Reardon, 1986, p. 714). Similarly, Miller (1987) denotes this form of coping in terms of “monitoring” referring to the behaviour to engage in information seeking activities when exposed to threats. Usually this form of coping behaviour is considered as a problem-focused form of coping. This means that the online information gathering and management is an effort to deal with the problem or the stressor (like illness) as such. To search for information and to bring it together and manage it creates a sense that the individual is actually doing something about the problem and that he/she is in control even though the situation is actually beyond control (Folkman & Moskowitz, 2004; Maes et al, 1996). However, this form of information seeking also has a dimension of emotion-focused aspects (Shoshana & Orgler-Shoob, 2006). This means that information seeking is performed also to deal with the emotions involved. In the study patients reports about the information seeking leaving them with a good feeling and it was used as a form of “self-therapy” reducing distress and feelings of fear.

An additional way to deal with the illness was the seeking of *social support*. Here, this involves interaction with fellow sufferers to deal with the stressful situation and the emotions it may cause. Searching for social support when facing illness signals a need for personal recognition (c.f Lazarus & Folkman, 1984; Maes et al., 1996; Snyder, 1999) from someone with whom the patient share the actual illness experiences. Further, social support on a peer-to-peer basis brings the patient an opportunity to relieve the pressure on family and friends (Sullivan & Reardon, 1986; White & Dorman, 2001). To share experiences and problems is believed to reduce uncertainty and even improve health related outcomes (White & Dorman, 2001; Sullivan & Reardon, 1986). In addition, social support might equip patients in their meetings with the healthcare and increase their abilities to actively participate in health decisions (Finn, 1999). This illustrates the multifaceted nature of social support involving informational support (like providing information, advice and feedback), and tangible support (involving direct forms of aid), and emotional support (including attachment and reassurance) (Schaefer et al., 1982). For the study participants the role of social support initially varied. However, the contact with fellow patients seemed to have an increasingly important place in the process of starting the online self-help groups.

A dimension of social support mirrored among the participants concerns the idea to *facilitate others*. As a strategy for coping Vaillant (1977) discuss this in terms of *altruism*, which he describes as “*getting pleasure from giving to others what you yourself would like to receive*” (p. 110). Schwartz et al. (2003) mean that altruistic behaviour is important to recognize as a coping strategy to deal with stressful situations since “*altruism can regulate people’s perceptions of those internal and external realities they are powerless to change, and empower them to effect meaningful change.*” (p. 778).

In the study the patients referred to the possibility to facilitate others as an additional driving force to initiate the self-help groups and to cope with illness. It

seems as if the initial coping strategy to search for factual information and social support grew into a need to let the information also benefit others. For some, the idea of supporting others with information and contacts means the most. To facilitate others is however, closely related to the own feeling of being helped by helping others. Reeves et al (1999) supports this in their study on the development of coping strategies among HIV-positive individuals. The authors found that the participants “*eloquently spoke of reaping personal benefit from helping others*” and that many “*associated altruism with the meaning they had made of their lives*” (p.357). Schwartz & Sendor (1999) make similar conclusions in their study on people with multiple sclerosis stating “*peer supporters reported greater benefit in quality-of-life outcomes than those they helped*” (p.1569).

In sum, the patients’ initiation of self-help groups online involves different forms of *problem-focused* and *emotion-focused* coping (Lazarus & Folkman, 1984). The problem-focused strategies involve management of external problems (like the lack of factual information about the disease, examinations, treatments etc.) as well as internal needs (like getting personal recognition, acknowledgment of experiences or increase the personal competencies). The emotion-focused strategies concerns coping with emotional responses of the situation like creating a sense of control of the situation or seeking emotional support.

The contribution of a coping perspective on the initiation of patients’ online self-help groups

As mentioned earlier, previous work on patient managed self-help groups on the Internet mainly concerns aspects of participation in the groups, the groups’ technical and social structure as well as their role in the patient-healthcare relationship. As a contrast the underlying personal and behavioural driving forces of the groups has been less explored. Possible reasons for this are that much of the research on this particular type of online groups resides in disciplines oriented towards other interests than behavioural or psychology related issues. In addition, in countries lacking the tradition of self-help (like the Scandinavian countries) these groups represents an emergent phenomenon with several areas left to be explored.

This study introduces the ideas of coping as a complementary perspective when investigating why patients’ initiate self-help groups on the Internet. First, as a general contribution coping adds a behavioural perspective on this particular form of Internet use related to psychological reasoning about how individuals manage stressful situations. It highlights that human behavioural processes are involved in people’s adoption and use of the Internet for illness management purposes. It provides the possibility to get a deepened picture of the role of the Internet in people’s lives when dealing with difficult life situations and brings new insights to our overall understanding of the IT user perspective (Beaudry & Pinsonneault, 2005). The study exemplifies this as the patients’ information

seeking efforts developed from a way to get personal answers into efforts to support others with information and communication. In terms of coping, the initial strategy to seek information grew in to coping involving forms of social support and ways to facilitate others. In addition, the patients indicated the role of the Internet in their lives as they expressed their information seeking efforts in terms of a “self-therapy” and how they were strengthened by their online information seeking.

Second, as a more specific contribution, coping in the present study elucidate aspects of the individual driving forces involved when patients initiate self-help groups on the Internet. That is, the coping perspective indicates that the groups depart from *individual* needs related to the personal coping process rather than group related interests. This implies that the initiation is a part of the patient’s way of coping with her *own* situation and not primarily efforts to start groups or to care for the patient groups per se. This relates to the example above where the initiators searched for information and contact for their own purposes and later made the choice to use the Internet to support others *as well as* themselves in an altruistic sense (Vaillant, 1977). Partly this contrasts other research on individuals’ initiation of groups online emphasising social aspects of interactions with others for different purposes as main driving forces of online groups (Baym, 1995; 1998, Preece, 2000). However, applying a coping perspective is not to say that the group is not important. Instead coping point at underlying *individual needs* influencing the initiation of this particular form of online groups.

Third, by focusing the initiation of the self-help groups and by doing it in terms of coping we are provided with human behavioural aspects important to feed in to discussions on how to improve technology and its use. For example, there are different emergent forms of Internet use supporting the communication between healthcare and patients. There are healthcare managed online web sites for medical information and healthcare services (Gruca & Wakefield, 2004) and the Internet is used in treatment situations (Kummervold et al., 2002; Leimeister et al., 2004) or as a tool for follow-ups or evaluations (Murero & Rice, 2006). To improve these and similar forms of Internet use there has lately been an increased focus on the need to strive for IT solutions supporting patient-centric (as opposed to institution-centric) information systems (Demiris, 2006; Johnson & Ambrose, 2006; Van’t Reit, 2001).

A coping perspective on the initiation contributes by providing the possibility to identify some of patients’ requirements in relation to Internet use. Here, coping strategies involving information seeking, social support and need to facilitate others, exemplifies this. Although the coping strategies are only briefly touched upon in this article and need to be further explored they highlight some interesting issues of IT use development. For instance, viewing the significance of online information seeking as expressed by the patients’, against the background of the vast amount of medical information online and the risk of misinformation (Murero & Rice, 2006; Morahan-Martin, 2004), indicates patients’ requirements

for support in their overall information seeking efforts. Here, healthcare providers could play an important role by supporting patients' information seeking coping by offering online guidance to reliable and useful sources. In a similar way the participants emphasize coping by social support when facing illness. To get in contact with others has been found beneficial for patients (Demiris, 2006; Finn, 1999; Kummervold et al., 2002; Leimeister et al., 2004) and as a *complementary* service this could be offered by healthcare providers as well. So far there are few examples of this though it has been stressed that the benefits of patients' exchanges in online self-help groups should be developed to reach other stakeholders in the healthcare system as well (Johnsson & Ambrose, 2006; Demiris, 2006). In addition, healthcare engagement in providing complementary online spaces for social support is a step towards a holistic view of illness and an opportunity to increase learning about the patient situation in healthcare practice.

Limitations and future work

The reported study involves a limited number of Swedish patient online self-help groups and their initiators. The interviews reflect the process of imitation in a self-reporting and retrospective manner. This brings a limited perspective as opposed to approaches where the initiation could be followed close to its immediate occurrence. In addition, the self-reported retrospective picture limits the possibilities to reveal how various coping strategies might be combined and changed over time.

Despite this, the article introduces an additional perspective of the initiation of this particular form of Internet use. However, to deepen our understanding of online self-help groups in terms of coping, additional studies should explore ongoing self-help activities as well. For example, analyzes of the writing process and narratives as forms of coping (Snyder, 1999) could reveal additional information. In addition, to provide a more thorough analysis, complementary studies are needed using both qualitative and quantitative methods.

CONCLUSION

Drawing on coping theory this article analyzes patients' initiation of online self-help groups. The main purpose of the article is to explore individual driving forces involved when initiating online self-help groups. In the study, three main coping strategies are identified, influencing the initiation of the self-help groups: *information seeking*, *seeking social support*, and *to facilitate others*. By means of coping literature the article presents a deepened picture of the strategies. It is argued here that a coping perspective on initiation elucidates that human response processes for managing stressful events are involved in patients adoption of the Internet for health purposes. More specifically, this means that a coping perspective indicates

that the initiation of self-help groups are driven by individual needs related to coping processes rather than group specific interests. Finally, this particular focus on patients' initiation of online self-help groups is believed to support the identification of patient-centric requirements for further development of Internet use in the patient-healthcare relationship.

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COPING WITH ILLNESS ONLINE: THE CASE OF PATIENTS' ONLINE COMMUNITIES

Ulrika Josefsson

Abstract

This article identifies and analyzes characteristics of patients' online communities (POC) in Sweden. Using a qualitative approach, it presents a fine-grained picture of the communities covering both the structural and cultural factors. Acknowledging the debate about quality of health information online and the potential risks of e-health, the article argues that a deeper understanding of the dynamics of POC, which offer unique aides for the coping process of chronically ill patients, can contribute to the design of the emergent forms of Internet-based health care resources.

INTRODUCTION

Today many people are involved in various online communities (OC)¹ such as web chats (Sveningsson, 2001), newsgroups (Baym, 1995, 1998), and MUDs (multi-userdungeons) (Reid, 1999) that “allow for people to create a range of new social spaces in which to meet and interact with one another” (Kollock & Smith, 1999, p. 3). In general these can be categorized as online communities of special interests in which people participate because they share a common interest. This article focuses on a specific kind of online self-help community where people are brought together more by coincidence and by reasons beyond their control—patients' online communities (POC)^{2,3}. These online communities might even be categorized as “communities of unintended interest,” referring to the (sometimes drastically and quickly) changed life situation not controlled by the individual.

Lately patients' online self-help has attracted an increased research interest. Studies have examined the benefits for patients to participate in POC (Ferguson, 2000) as well as specific self-help processes (Preece, 1999; Finn, 1999) in such groups. Additional studies have focused on the quality of the medical information (Eysenbach & Diepgen, 1999) and the transformation of the patient role (Hardey, 2001) due to online participation.

Despite the increased research interest, little attention has been paid to the structural and cultural aspects of POC (Burnett & Buerkle, 2004). Also, few scholars have focused on how an increased knowledge of POC can inform the design of emergent health care resources on the Internet. Although the Internet is a powerful instrument for enabling interaction between people and organizations (Kahn, 2000), it is still underused when it comes to the relationship between patients and health care (Rice & Katz, 2001). Several studies emphasize the need to use the Internet more effectively in this area (Leimeister et al., 2002; Sittig et al., 2001; Eysenbach & Diepgen, 1999; Ball & Lillis, 2001). In order to meet patients' specific needs, their participation in the development of online healthcare resources is important (Leimeister et al., 2002). Accordingly, this article seeks to increase our understanding of the specifics of POC as a unique type of online community and to use this knowledge to develop guidelines for design.

To accomplish this objective, Baym's (1995, 1998) model of "the emergence of on-line community" is used to explore the structure and cultural dynamics of POC. The article is structured as follows. First, the performed research study is outlined followed by a presentation of Baym's model. The model is then applied in order to examine the characteristics of the participating Swedish POC.⁴ Finally, there is a discussion about distinctive features of POC and their significance for design.

THE RESEARCH STUDY

This article is based on data from three related research studies performed during 2001 and 2002 (Table 1).

The first study involved observations of Swedish POC on the Internet. Its objective was to examine how online communities were initiated and managed by individuals addressing a particular disease or patient group. With the help of Internet search engines such as Altavista, Google, and Yahoo, 15 POC representing chronic health disorders such as multiple sclerosis, endometriosis, fibromyalgia, and whiplash were selected. The selected POC had been online between 2 and 7 years. The observations generated an initial understanding of the structures and the performed practices within POC.

The second study administered an exploratory questionnaire with open-ended questions in 4 (of the 15) POC—2 discussion boards and 2 e-mail lists. It sought to understand patients' experiences and expectations of the use of online medical information and also to elicit their ideas of how to use the Internet

health care interactions. The questionnaire resulted in 39 answers that were less than expected. It is difficult to estimate the actual answer rate since two of the participating communities were open to all visitors to the web site. The other two communities (the e-mail lists) had a total of 205 members at the time the study was conducted. However, even though the questionnaire was limited in several respects, the participating patients provided rich pictures of their experiences of various online medical resources. This study served as an important introduction to the area and provided guidance for future work.

Method	POC/interviewees/ answers	Question areas
Observations	15 POC	Structural design/ performed practices/ what the POC offer visitors or members in terms of interaction and information.
Questionnaire (Open questions)	4 POC (2 e-mail lists and 2 open discussion boards) 39 answers	Patterns of Internet use for medical information/ pros and cons/ effects on healthcare provider- professionals relationship/ ideas for future Internet use by patients/health-care.
Semi-structured interviews	10 interviews with initiators of 10 POC	Why and how the POC was started/ how the POC has developed/ technical and social structure/pros and cons/ future of the POC.

Table 1. Summary of research studies.

The third study involved 10 semistructured interviews with the initiators⁵ of 10 of the 15 previously observed POC. Five POC decided not to continue their participation in the study. Seven of the interviewees were women and three were men, and the ages varied between 25 and 65. The interviews focused primarily on how and why the communities were initiated and how they have developed since their establishment. There were also questions on social and technological issues of online communities, reaction of the medical establishment to POC activities, and future possibilities. Each interview lasted for about 45 to 70 minutes and was tape-recorded and transcribed.

THE EMERGENCE OF ONLINE COMMUNITY

Drawing on the work by Contractor and Siebold (1993), Hollingshead and McGrath (1995), and Siebold et al. (1994), Baym (1995, 1998) has developed the “emergence of on-line community model” while grappling with the question, “What occurs online that leads some people to experience them (online communities) as communities in the first place?” (Baym, 1998, p. 38).

In computer-mediated communication (CMC) research a technology deterministic tradition has dominated (Baym, 1995). In contrast, Baym’s work takes a constructivist perspective and emphasizes the emergence of an online community as a complex interplay between participants, context, and technology. The underlying idea of Baym’s model is that different cultures emerge in online communities and that these cultures are grounded in communicative practice. This practice can be described as interplay between the preexisting structures of the community and the participants’ appropriation and use of the resources and rules offered by the structures.

Baym (1995, 1998) starts by identifying five preexisting structures of online communities—external context, temporal structure, system infrastructure, group purpose, and participant characteristics. Here is a brief overview of each of these structures:⁶

- *External context*: Reflects the online environment in which the communication is situated, such as the technical and social practices along with group relevant resources brought into the online community by its participants. This issue also concerns the location of the immediate access to the technology.
- *Temporal structure*: Involves the possibility to communicate synchronously or asynchronously, influencing the number of participants as well as the access to immediate feedback, and the possibility to write and rewrite messages. Also, this issue concerns the maintenance of archives that afford the opportunity to visit past discussions.
- *System infrastructure*: Concerns the configuration and flexibility of the technology in addition with user-friendliness.
- *Group purposes*: Refers both to purposes basic for the existence of the community and to the purposes that emerge through interplay between the participants.
- *Participant characteristics*: Relate to different experiences and knowledge of the community theme along with diversity of social and geographical residence of the participants. Additional characteristics concern the size of the group

and different experiences of information technology use, along with differences in age, sex, and education.

The five preexisting structures are closely intertwined and related to each other. Together they set a complex basis for the study of important components in order to understand the emergence of an online community. However, these structures are not enough since the social dynamics of a group also need to be considered. According to Baym (1995, 1998), they are the result of the participants' appropriation and use of the resources and rules offered by the preexisting structures. Drawing on CMC⁷ research work, four categories of social dynamics are suggested and discussed. These categories, which are briefly discussed next, are forms of expression, identity, relationships, and behavioral norms.

- *Forms of expression:* Relates to the development of “group-specific vocabulary,” “unique forms of jokes,” and also social cues like the use of nonverbal information such as smileys.
- *Identity:* Concerns how a name is created or how participants get “famous” in the group. The identity creation also concerns how anonymity and made up identities are treated in the community.
- *Relationships:* Treats how relationships are developed and maintained and how online relationships go offline as well as situations when the opposite occur.
- *Behavioral norms:* Reflects what is socially accepted in the community, often summarized in the “netiquette,” along with technical rules that regulate the online communication.

In multiple ways these four categories are continuously influenced by the preexisting structure of the online community. This brings a complex picture of how these online phenomena must be analyzed and understood. The next section starts with a vignette of the initiation of a POC. Then the model is applied to capture some important characteristics of the structures and cultural context of online communities designed by patients themselves.

PATIENTS' ONLINE COMMUNITIES (POC)

The following vignette illustrates a typical scenario for the start and initial development of POC analyzed in this article. It provides a short summary of some central experiences shared by patients in the study.

In spring 1998 Lillian was diagnosed with multiple sclerosis (MS).⁸ She was then 30 years old. She left the doctor's office with his comforting words of "now, go home and rest and call me if you have any questions" ringing in her head and a little blue brochure in her handbag. Inside she felt how her world started to fall to pieces. Suddenly there were so many questions! What would happen now? What would she do? How could she tell the others? Her husband? Her children? The rest of her family? And what about her job? And what did the doctor say about further examinations and available treatments . . . ? She thought she remembered everything that man said; now she suddenly found herself unable to recall a single word.

After the initial shock she started to realize that she herself must learn everything there is to know about MS and what she was dealing with. She needed both the medical facts as well as the opportunity to learn from others. At that point in time, she had a vague idea that the Internet could be useful because of exposure to media coverage and conversations with friends and family. She got herself a computer and an Internet connection and then started working her way through the vast amount of medical information online. At her office Lillian was using computers, although the Internet was not yet part of her daily routine. Her first moves online were fumbling and her initial attempt to find information about MS was limited to writing the diagnosis in the Google search engine. After that, she went to all kinds of web pages—everything from private homepages to medical databases and journals. There were stories provided by fellow patients together with scientific papers. Some of the information she translated into her own language.

Searching the Internet, she had a hard time to find the kind of web page she was looking for: a web page—in Swedish—providing both specific information about MS and personal stories as well as the opportunity to get in contact with fellow patients. Through her online activities she had learned how the technology could be used, and with some help from a friend the first steps toward the online community for MS were taken. In the beginning, the web pages were quite simple, with all sorts of information about MS. After some time, Lillian set up the MS discussion board to simplify the communication between patients who had contacted her using the e-mail. They shared their experiences, and shortly afterward Lillian also started an MS mailing list. Today her community has 487 signed up members, each with their unique experience of MS. Lillian spends several hours a week with her patient community, and sometimes she feels that it would be nice to "take some time off." However, after the 6 years that have passed since she started and after the ample evidence she has received from other patients about the importance of her community, she wants to go on.

Preexisting Structures of POC

External Context. The preceding vignette highlights three central features of the external context of POC: the driving forces, the sum of experiences available in the communities, and the Internet environment in general.

The specific driving forces and their dynamics distinguish POC from other types of online communities (OC) (Preece, 1999). These communities are initiated and maintained because people are confronted with a changed life situation (sometimes drastically and overnight) due to illness. A chronic disease

often raises new needs and demands, and the individual must find ways to cope with the illness and the new life situation (Lazarus & Folkman, 1984; Gullacksen, 1998). Therefore, along with Preece (1999), it is argued here that although the web design and the use of different interactive facilities might appear similar to other online communities, the driving forces of POC are very different from other online communities of shared interest.

One of the major coping strategies⁹ of the patients is to get more information and to learn about the disease. They search for medical facts and social support, as well as information on how to manage everyday life. Maria (initiator of a POC for multiple sclerosis) explains that she searched the Internet for information about multiple sclerosis because *“I believe it was my way of making sense of what I was facing.”*¹⁰

The search for medical information was described as an activity initially carried out to learn as much as possible about the disease and later also to be able to discuss it with (in contrast to ask) their doctor (Anderson et al., 2003). In the study the search for information was also referred to as a “treatment,” described by David (initiator of a POC for whiplash) as “one of the most important components of my own therapy.” However, the risk of unreliable medical information and the difficulty of finding information presented in a way that is accessible to laypersons made the search challenging (Eysenbach & Diepgen, 1999). The following excerpts from the questionnaire highlight this:

“It is disappointing that there are only a few doctors active on the Internet for counseling, answering questions, etc. There are many laymen who know a lot but there are also many who just think they know what is best. There is a risk that the advice provided is for everyone!”

“The health care and the research community should provide information easily accessible by translating it into a non-academic language. The research community must realize that patients want information without the need for a professional translator in order to understand.”

Further, the vast amount of medical information online was seen as a challenge with the attendant risk of information overload. For instance, there is the risk of getting information that the individual is not ready for (Leydon et al., 2000), due to a certain stage or phase of the disease:

“There is risk of being flooded with information. Much depends on your personality. Reading too much about PCO [polycystic ovary syndrome] and all possible medical complications has not always been good. I have as a nonmedical professional not been able to sift out information in the best way.” (excerpt from the questionnaire)

Another coping strategy employed by the patients is to get in contact and interact with others facing the same or similar situation. Several research studies report the health benefit from such social support (Pierret, 2003; Eysenbach et al., 2004; Reeves, 2000). The patients describe the opportunity to lurk (Preece et al., 2004) and to “silently” follow a debate or read someone’s personal story of illness as a good way to get informed and to learn about the disease as well as to get their personal experiences confirmed. Susan explains why people join her POC for patients with fibromyalgia:

“They look for contact with other patients. Some simply want to read. On the page “Others’ stories,” they can read about this [fibromyalgia] happening to other people as well. It is very comforting since you feel like the loneliest person in the world. And you think that this happens only to me.”

In addition, POC allow for patients to help others, which has found to be an equally important coping strategy. For instance, in a study of HIV-positive individuals, Reeves (2000) found that a central aspect of the patients’ use of the Internet was that “it facilitates helping others” (p. 56) and that the patients found this most rewarding. This is supported also by the present study of POC. In the study, the interviewed initiators and the participants of the questionnaire often pointed out: *“I want to help others so they don’t have to go through the same thing I have.”* This is highlighted also in the following excerpt from Maria (initiator of a POC for multiple sclerosis):

“It makes me happy to be able to help others. For me . . . I am past the worst . . . but I know how hard it was and every time I get an e-mail from someone who thanks me it is most rewarding . . . it is a very satisfying feeling.”

Supporting each other also contributes to the sum of experiences available in POC. The sum of experiences is created as patients tell their story of how they discovered the disease, about their meetings with health care providers/professionals, how they were examined and diagnosed, and how they have experienced different treatments. In addition, these informative practices are supplemented by an interpretive practice (Hardey, 2001). Here the patients draw upon their own and others’ experiences of the disease to help fellow patients to interpret what doctors and other health care professionals are saying about test results, examinations, and other such subjects.

Irene is an initiator of a POC for women suffering from endometriosis, and she describes her ideas of the sum of experiences as follows:

“All the girls on the mailing list have something to give. They have knowledge and they have been through things or taken certain medications [. . .] everything they have been through can be used for good things.”

The Internet environment in general and the fact that POC, like other online communities, function on a geographically dispersed basis influence the sum of experiences also. This means that participants have an opportunity to learn from fellowpatients about health care delivery and treatments available in other parts of the country or the world (Hardey, 2001). Participants of the POC in the study come from all over Sweden, although some communities also have members from other Scandinavian countries and Swedish citizens living abroad. A few of the POC also have members of other nationalities living in other parts of the world.

As highlighted by the vignette, the participating patients get online from their homes as well as their workplaces but rarely from publicly accessible computers. Statistics of Internet use in Sweden also support this. For instance, Sweden Statistics (2004) reported in a study of Internet access among 3767 individuals (16–74 years old) that 65% used the Internet at home, 36% at work, 13% at school, and 8% in other places.

Temporal Structure. The possibilities to communicate asynchronously (discussion boards, e-mail lists) and synchronously (chat) in POC are similar to those in other online communities. However, these facilities involve some unique benefits corresponding to patients' special needs and demands in their difficult life situations. For instance, coping with illness involves a process of reappraisal of the self (Wright, 1983). This involves a dialogue with others, where the patient tests the logic of his/her sensemaking of the illness and the new situation he/she is facing (Gullacksen, 1998). The possibility to share experiences is found to be most useful in defusing fears, especially that of being deviant (Wright, 1983). This sharing not only informs but also creates a sense of belonging (Gullacksen, 1998). The temporal structure offering both asynchronous and synchronous communication provides the opportunity to participate and/or follow(also earlier) discussions at any time. This is highlighted by one of the participants in the questionnaire, who said, *"I use the Internet to get a sense of belonging, especially since I know nobody else with the same diagnosis."*

In addition, the patients in the study emphasized that many questions become important after leaving the doctor's office and uncertainties or anxiety may occur at any time. Therefore, they find it important to knowthat *"someone is always out there for you"*:

"The reason for me to go online is that it is easy to access and often there are questions after the visit at the doctor's office that you can find answers to in these discussion groups." (extract from questionnaire)

System Infrastructure. The resources available to each of the POC determine the features of the technology, such as user-friendliness, that sustains the online community. For instance, the initiators' time resources, strength, and energy to work with the community and their access to, and knowledge of, the technology

affect the design of the POC. While some initiators learned to use the technology as part of their professional work, others acquired the necessary knowledge via trial and error and help from family and friends. As explained by Tom, who started a POC for patients suffering from chronic prostatitis:

“My son is only 21 years old, so I said to him, “How do you make a homepage?” “Well, I can teach you how to do that,” he said. So, we got this thing called Front Page and made a lot of mistakes [. . .] but eventually we got it running and he helped me to put in some pictures. So, it [the POC home page] started with two or three pages and today it has several hundred.”

Concerning the system configuration, some of the interviewees described how their POC are built mainly using free software available on the Internet, while others spent private means to get the system infrastructure in place. In addition, the physical location of the web pages varies. For example, some are located on free servers in exchange for commercial advertising on the web pages, while others pay for a web hotel to avoid this. Some have also bought their own domain names. This variety indicates that POC have different potential to offer their patients a well-organized online community. Accordingly, patients with some diagnoses find information and support in professionally developed web pages, while other groups of patients have to work with a simpler structure and system configuration. A well-designed system does not automatically translate into a supportive POC. Nevertheless, design issues are known to be important factors for the use and further development of online communities (Preece, 2000; Kollock, 1998).

Group Purposes. The general purpose of a POC is to support and help people in difficult life situations caused by illness or injury. However, as noted by Baym (1995, 1998), online communities may have several purposes. For the participating POC, four specific purposes have been identified: to provide social support, to inform, to learn, and to influence the public opinion. These purposes can be described as variations of the general purpose. Also, they are intertwined and more or less explicit in each POC.

The most evident purpose of the POC in this study is that of providing social support. Some of the interviewees described this as:

“My aim is not only to provide facts but also . . . even more importantly . . . they [the POC participants] should get response from someone who understands the hell they often go through.” (David, initiator of POC for whiplash)

“By discussing PCO and share our experiences we can help and support each other.” (Annie, initiator of POC for polycystic ovary syndrome)

The idea is to support discussions and personal interaction and to serve as a meetingplace for fellow patients, providing support and human understanding. This purpose becomes visible in the different interactive facilities provided by the online communities, and sometimes it is explicitly stated on the homepage:

“Here we are free to discuss everything under the sun. What it is like to live with fibromyalgia but also other small and big issues of the everyday life. We support each other whole-heartedly.” (web page of POC for fibromyalgia)

A second important group purpose in all of the participating POC is to inform patients in different ways about the disease.

“On this homepage I try to gather information to provide an opportunity for those who wish to ask questions and hopefully get some answers.” (web page of POC for myalgic encephalopathy/ chronic fatigue syndrome)

The basic idea is to help patients become well informed and to increase their abilities to handle their situation as patients and to make informed choices in the health care system. This purpose is communicated via the text on the “welcome page” and also in the design of the community pages having links to pages about “symptoms,” “diagnosis,” “treatments,” “the disease,” and “latest news from the research.”

The purpose to inform is closely related to the purpose of serving as an online learning environment. On the homepage of a POC for people suffering from panic disorder, this is described:

“The principal aim of this site is that you can continue to learn actively about panic disorders and become your own expert. Although you cannot treat yourself, you are the one who knows your needs best. Once you have gathered information and ideas you can attack the situation and choose the most suitable way to get well.”

This purpose is thus pointed out in the online community by emphasizing the idea of patients using the web pages in order to become “their own expert.” Also, the extensive lists of links to other sources of medical information, sometimes referred to as “recommended readings,” make such purpose clear.

Finally, the purpose to serve as a means to influence the public opinion is explicit in some POC. Since some diseases or situations for the patients are not well known, there is a need to create “disease awareness” among patients as well as in the society. David (initiator of POC for whiplash) illustrates this purpose as follows:

“My interest and focus today is to prevent others from experiencing what I had to go through. I want to help others overcome all the trouble with physicians without any knowledge of whiplash associated problems and syndromes; rehabilitation, social security, and insurance companies. In Sweden I try to raise opinions in order to influence media and politicians in these matters.”

These issues are also the topic of much of the information available on the web pages. For instance, there are comments about when the disease has attracted attention in mass media and there are reprints of articles available originally published in newspapers. There is also information about legal cases concerning the disease. These different purposes imply that although POC share the general purpose of supporting and helping people in difficult life situations, the activities take varying directions (Burnett & Buerkle, 2004). This means that POC should not be considered a homogeneous group of online communities, but instead their differences should be acknowledged and further explored (Preece, 1999; Burnett & Buerkle, 2004).

Participants Characteristics. POCs provide the opportunity to get in contact with all sorts of participants. Some patients have long-time experience and others are newcomers. There are also participants from around the country and the world. There are active participants as well as lurkers. Also, POC provide contacts with patients with whom the participants might share life experiences in general. For instance, there are participants with a specific work situation or unemployed, people with experience of a certain disease and parenthood, or people struggling with both the disease and experiencing infertility problems, and people who went through other difficult life events such as divorce.¹¹

The significance of getting the personal experiences of an illness confirmed and of reaching out to others has been noted. However, these needs for contact can be difficult for the health care sector to meet because of such reasons as limited time and financial resources, restrictions on patient information, etc. This means that POC have the potential to serve as an important arena for social interaction since they provide a wide spectrum of participant characteristics (Finn, 1999) and thereby increase the possibility for the patients to find stories and experiences they can relate to.

Social Dynamics of POC

The preexisting structures represent the basics of POC. However, alone these are not enough to give a comprehensive view of the communities. In order to deepen our understanding, the social dynamics of POC should also be examined. In the following discussion we examine the forms of expression used, together with identities, relationships, and behavioral norms.

Forms of Expression.

“There is a really nice atmosphere . . . very close and you trust each other and all that.” (Ellie, initiator of patients’ online community for whiplash)

Sharing stories of illness means that participants in POC provide personal and sometimes delicate information about themselves. The participants are well aware of each other’s difficulties and what everyone is going through. The combination of these elements and their desire to help others generates the empathic (Preece, 1999) forms of expression applied in POC.

The observations and the interviews showed that the use of a medical language and terminology for medical texts, examinations, and treatments also distinguishes the forms of expression in POC. As a complement to other informative practices in POC, this form of expression contributes to POC serving as a space for health education (White & Dorman, 2001), helping patients understand the specifics of the disease.

Humor is an important feature of POC. Jokes about the disease and funny stories about how patients have been treated by health care professionals are common. These stories report comments or medical advice from doctors or other health care professionals considered completely wrong and ridiculous by the patients. These stories become group-specific jokes, and in some POC they have their own special web page. The following extract is from a web page titled “Blunders from doctors and others” in a POC for patients with endometriosis: *“There is a huge ignorance about endometriosis sometimes even among the doctors themselves. . . . Here we have collected some comments we have been provided.”*

The use of humor among the participants can be understood as a way to manage the power relationship between the patients and their doctors and other professionals. Consequently, this indicates that the use of humor is a form of resistance toward the traditional knowledge and power domains (Griffiths, 1998).

Identities. In general the identities in the participating POC can be described as oriented toward anonymity:

“People want to be anonymous. When you look for medical information on the Internet perhaps you just want to read a little and then you want to go back there but you don’t want to keep on doing these registration procedures everywhere.” (Margret, initiator of POC for panic disorder)

In addition, the particular medical diagnosis influences the ideas of anonymity in POC. For instance, diseases involving delicate issues such as infertility problems, impotence, or mental disorders are likely to result in less self-disclosure (White & Dorman, 2001; Finn, 1999).

Further, in POC the participants play different roles similar to those found in online communities in general. Preece (2000) captures some of these roles under

the headings of moderators, mediators, professionals, lurkers, and participants. However, the development of the roles in POC is related to the personal style of the community owner. His or her strategies for how to run the community are central. An example is decisions about such things as whether the community should be open to any visitor or if a membership should be required. Ellie (owner of a POC for whiplash) emphasizes active participation as a key criterion when accepting new members of her POC. She describes her strategy as follows:

“They should post to the mailing list for some time and show that they are active. Activity involves both asking and answering. Not just to give answers and not only to ask. You have to share, you know.”

Consequently, the work to initiate and run a POC also creates the identity of the owner. He or she takes a leading position and becomes a central person not only for managing the online community but also as an important support person for patients needing help. For instance, the owners are often the first to get in contact with new participants in need for information, support, and human understanding.

Relationship. As indicated earlier, the relationship between the participants and the owner is an important feature of POC. Often the initiator takes on a heavy burden, trying to support, comfort, help, and “push” others. They deal with both worried relatives and distressed fellow patients, sometimes feeling badly treated or neglected by doctors and health care. Margret and Irene describe their experiences of this:

“It’s frustrating when someone again and again says “I feel so bad and depressed” and there is nothing you can do . . . but to tell them to “go for help” or to call this or that clinic [. . .] but you are never sure if they do [. . .] I mean, I can only help to a certain degree, then they have to go for professional help [. . .] I am not a doctor.” (Margret, POC for panic disorder)

“Suddenly the mailing list became very difficult for me. I felt a bit like “the mother” of the mailing list. I mean, I went through the same thing as everyone else but after a while it seemed as if I was not allowed to complain—someone had to play the role of the strong one all the time.” (Irene, POC for endometriosis)

Behavioral Norms. Emphasizing the necessity of etiquette online, Preece (2004) recently wrote:

“The complexity of this rich m’elange of users, goals, technology, and access conditions presents new challenges to etiquette online, particularly for the growing number of support communities where kindness, help, and empathy is anticipated. Good approaches for fostering etiquette online are therefore needed.”
(p. 57)

The patients in POC showed awareness of the drawbacks of online communication and interaction. They have experiences of flammers, annoying behavior, and participants pretending to have the shared illness (Burnett & Buerkle, 2004). Therefore in POC there are both technical and social guidelines on how to participate. The technical part involves such instructions as how to quote others when answering e-mails and how to correctly make contributions on a discussion board. Lists for “netiquette” serve to inform the participants about what is and what is not socially accepted in the discussions.

In POC it is also pointed out that since the participants are sometimes in a very difficult life situation and some issues discussed concern delicate patient information, it is even more important to be civil. This is illustrated by two extracts from POC web pages:

“Keep in mind that people with anxiety, depression, and phobias are very sensitive to criticism. Try to stay objective and nuanced.” (POC for patients with panic disorder)

“We are a vulnerable group of people so please avoid the use of emotive words that might hurt others.” (POC for patients with multiple sclerosis)

Since POC aim to provide empathy and human understanding for patients challenged by illness, the maintenance of the behavioral norms becomes important. The tools available for such process in the studied POC involve several components. First, there is the central role of the owner, functioning also as a moderator of the discussions. Second, there is the “core group” of participants who actively participate in the discussions and answer many questions. They help the owner moderate the discussions and rein in participants who go to far. The POC owner also gets some help from technologies that do such things as approve or reject messages. These tools for creating etiquette online are (among others) emphasized by Preece (2004). However, the problem of sustaining the behavioral norms in POC is much too dependent on the capacity and strengths of the individual owner. Since POC represents a kind of online community where the needs for behavioral norms are most important,

this is unfortunate and contributes to the vulnerability of the communities. Thus, along with Preece (2004), it is argued here that “*the way forward is to develop processes that bring together the best human-oriented approaches with good technical support. New processes must include rich social structures as well as be labor-saving and scalable*” (p. 61).

DISCUSSION

Facing chronic illness generates certain needs and demands that contribute to the creation of the POC. This makes them a unique type of online community and an emergent online phenomenon (Preece, 1999). Baym’s model helps us analyze the structure and culture of these communities.

POC bring together a rich collection of medical information from offline and online sources. They include online discussions and sharing of personal stories and experiences. This means that POC provide an extensive mixture of translated, rewritten, and combined medical information, together with personal experiences and beliefs about the disease.

This collected mixture of lay and professional knowledge makes POC an interesting phenomenon where the Internet allows e-health consumers to turn into producers of medical information (Hardey, 2001). Even more importantly, the mixture plays a central role by meeting patients’ requirements for *specific* experience and knowledge (Leimeister et al, 2002; Ball & Lillis, 2001) about a certain health condition, in contrast to many web pages providing *general* information.

This creation of “personal” collections of information is a product of patients finding their way on their own through the vast amount of medical information on the Internet (Reeves, 2000). This process entails a personal way of judging the quality of the medical information found on the Internet (Eysenbach & Kohler, 2002). For the design of emergent forms of Internet-based communication between patients and health care providers, this suggests a careful consideration of patients’ *specific* needs for information and guidance toward appropriate web sites (Ball & Lillis, 2001; Leimeister et al., 2002).

The possibility of receiving comfort and human understanding from others and the opportunity to help fellow patients in the same situation have proven to be important factors when facing illness (Finn, 1999; Madara, 1997; Kummervold et al., 2002; Wright, 1983). By analyzing POC, designers can learn how to create additional spaces for interaction that can be used in the treatment process (Kummervold et al., 2002). Such spaces could also involve health care professionals. However, this is *not* to suggest the replacement of existing POC managed by patients on their own but rather to develop complementary resources. According to Mittman and Cain (2001), this area of community

building for patients and caregivers belongs to one of the “*leading-edge applications associated with the future of the Internet in healthcare*” (p. 48).

Both the content and the form of the medical information in POC make them a valuable learning environment: the content by providing extensive and specific information, and the form by allowing different learning styles such as active participation as well as lurking (Preece et al., 2004). POC experience suggests that designers need to keep in mind that patients have different strategies for using the Internet for self-help purposes. Therefore, the design should aim to support individual needs. For instance, this should include different views on anonymity and participation in online activities (Preece et al., 2004). The individual needs of the patients are also related to the disease in question as well as to different stages or phases of the disease (Leydon et al., 2000). By paying additional attention to these individual needs, there is an increased possibility to reach those difficult to reach (White & Dorman, 2001).

On the societal level, POC are a space for health education as they provide new possibilities for individuals to act against health care and other societal institutions (Josefsson & Ranerup, 2003). For instance, by learning about examinations and treatments available in other parts of the country or the world, the patients have the opportunity to put new demands on health care providers and institutions and thus challenge traditional knowledge domains (Hardey, 1999).

In spite of all the benefits of POC, we need to be mindful of the challenges and risks they pose. First, there is the risk of dissemination of misleading and dangerous information (Eysenbach&Diepgen, 1999; Hardey, 2001). This can be a result of deliberate actions to mislead (Burnett & Buerkle, 2004) or lack of medical knowledge and evidence (Finn, 1999). Second, POC contribute to the total amount of medical information on the Internet, providing additional voices and opinions for the patient to consider. For some patients the resulting information overload is a stress factor that is difficult to deal with (Henwood et al., 2002). Third, it must also be recognized that large groups of patients do not have the necessary resources to participate online. There is a risk that the use of e-health is taken for granted (Henwood et al., 2002) in discussions about patients’ online activities and their participation in POC. Finally, the fact that not everyone has the resources to utilize the Internet for health purposes highlights the risk of inequalities in access to health care resources (Hardey, 2001).

Limitations and Future Work

The emergent forms of Internet-based communications between patients and health care providers should be studied from technical as well as social perspectives (Preece, 2000). Mainly emphasizing the social, this article contributes by drawing attention to the specifics of POC as a unique kind of online community. But the perspective is broad and each of the identified POC dimensions needs to be studied in greater depth. Also, this introductory study

involves only a limited number of Swedish POC, focusing on different medical conditions lumped together in a broad category. Since POC should not be considered a homogeneous group of online communities, the particulars should be further explored from a comparative perspective. Thus some important questions for the future are: What can we learn from comparing POC focusing on the same disease? What are the specifics of male and female POC? How are POC used as online health resources with respect to their different purposes? Answering these and similar questions will further our knowledge of POC as an online phenomenon and support the design of emergent Internet-based health care resources.

Finally, this study uses a qualitative approach and is based on self-reported experiences of POC participants. In order to draw a more comprehensive picture, future work should also employ quantitative approaches (Eysenbach et al., 2004).

CONCLUSIONS

In this article the characteristics of POC in Sweden have been identified and analyzed using Baym's (1995, 1998) model for the emergence of online community. The main purpose of the article has been to increase our understanding of the specifics of POC as a unique type of online community. By applying the model, the article presents a fine-grained picture of the communities, covering both the contextual structures and the community culture. Further, the model contributes by highlighting important features of POC central to patients' coping processes. First, POC provide patients with specific medical information related to their illness, involving both medical facts and human understanding. Second, POC involve spaces for social support, providing the possibility to receive support as well as to help others. Third, POC also represent spaces for health education, with implications on the individual and societal level. Allowing different learning styles such as active participation as well as lurking, POC support individual needs for the learning process about a disease. These features are believed to contribute as guidelines for design of the emergent Internet-based communication between patients and health care providers.

NOTES

1. In this article the concept of "online community" is defined in accordance with Preece (2000): "An online community is a group of people, who come together for a purpose online, and who are governed by norms and policies" (quoted in Sieckenius de Souza&Preece, 2004).

2. Although notions like “self-help groups” (Finn, 1999, p. 221) or “social support groups” (White&Dorman, 2001, p. 693) are sometimes used, the term patients’ online communities (POC) is preferred in this article because it spells out the exact nature of the community that is the object of the study.
3. “POC” refers to both the singular and the plural forms of patients’ online communities.
4. Although Scandinavian countries do not have the self-help tradition of Anglo-American countries (Kummervold et al., 2002), Swedish POC are a particularly valuable case study because Sweden and other Scandinavian countries have broad access to the Internet at workplaces as well as in households and public spaces (Sweden Statistics, 2004).
5. Throughout the article the term “initiator” is used synonymously with the term “owner,” both indicating a person who has created and manages a POC.
6. For a comprehensive reading of the model, see Baym (1995, 1998).
7. Baym refers to Reid (1991) on work of Internet relay chat (IRC), Myers (1987a, 1987b) for the study of BBSs (bulletin board systems), and Hellerstein (1985) on a study of a university-wide network.
8. “MS is the result of damage to myelin—a protective sheath surrounding nerve fibres of the central nervous system. When myelin is damaged, this interferes with messages between the brain and other parts of the body. For some people,MSis characterised by periods of relapse and remission while for others it has a progressive pattern. For everyone, it makes life unpredictable,” (quote from <http://www.mssociety.org.uk>, accessed 30 May 2004).
9. “Coping strategies” here refer to the work by Richard S. Lazarus and Susan Folkman on how people act in stressful encounters (cf. Lazarus & Folkman, 1984) such as facing illness.
10. Since the research study was performed in Swedish, all quotes presented from the observations, the questionnaire, and the interviews were translated into English by the author.
11. These characteristics were revealed to the author in the questionnaires and during the interviews, although they were not specifically asked about.

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CONSUMERISM REVISITED: THE EMERGENT ROLES OF NEW ELECTRONIC INTERMEDIARIES BETWEEN CITIZENS AND THE PUBLIC SECTOR

Ulrika Josefsson & Agneta Ranerup

Abstract

An important transformation of the welfare state of today is the marketisation reforms many times strengthening the role of citizens' preferences in their choice of public services. Another important transformation is the new electronic intermediaries between citizens and the public sector that have emerged during the last few years. This paper focuses on intermediaries between citizens and the public sector when viewed in a quasi-market perspective. Our objects of study are Swedish patients' online communities and public portals for educational opportunities representing different forms of ownership. The aim of the paper is to problematize the capacities to act that citizens are provided with by means of the new intermediaries. We argue that the forms of citizens' influence induced by the marketisation reforms and the new electronic intermediaries provide capacities to act that have previously only to a limited extent been discussed in a systematic manner. In this paper the supplementary role of consumerist activities compared with e.g. representative and deliberative democracy is acknowledged. However, we conclude that the intermediaries are sophisticated instruments in a learning process that support the citizens' development into active consumers of public services.

INTRODUCTION

Citizens within the representative democracy, according to a simplified traditional view, have two basic roles as voters and service users. As voters they form an electorate [2,27] but are according to more deliberative ideals thought

of as partakers in a political debate thus strengthening the participatory element in democratic activities [8,31]. The elected politicians control the rest of the process by deciding about the framework for the public service provision, whereas the public servants administer and produce these services [2]. However, in this paper we argue that two phenomena affect the roles of citizens as well as their capacity to act in a democratic system of government. First, a profound transformation is the new institutional arrangements in the form of marketisation reforms affecting the administration and production of public services in many countries [2,4,23]. Such arrangements are characterized by different forms of demand/supply mechanisms, many times strengthening the role of citizens' preferences in their choice of public services either through mechanisms for citizens' direct choice of services or through a mediating, contracting agency. The arrangements are often denominated as social markets or quasi-markets [23].

A second phenomenon affecting the roles and capacities of citizens is, we argue, the emergence of new forms of electronic intermediaries between citizens and the public sector [2] when viewed in a quasimarket perspective [23,32]. Traditionally, in the research field of electronic government, the concept of electronic intermediary refers to phenomena such as publicly owned websites or portals providing general information about local or central government activities [14] or functionalities by which to obtain strictly defined services [3,39]. Alternatively, in the research field of electronic democracy the concept refers to electronic intermediaries that are connected to agencies within the local and national political process [8,26,31]. In contrast, these newtypes of electronic intermediaries are initiated not only by public agencies [29,32], but also by private agencies like companies and semi-private, non-commercial agencies using e.g. the Internet, www, chatt forums, e-mail lists [17,19,20,22]. The electronic intermediaries are in different ways related to public services produced within quasi-market arrangement including some degree of citizens' choice [29,33]. Most importantly, this mean that they provide citizens with new sources of information and other forms of support that might be of value in the choice of these public services as well as to enhance their position in other ways [32].

With this as a background it is interesting to notice that Anttiroiko in a recent article discusses both traditional, representative forms and newer forms of democratic influence that citizens might exercise by means of e.g. information technology. In the concluding comments on the multi-faceted future of electronic democracy he identifies a new, supplementary type of citizens' influence induced by the marketisation reforms and the new electronic intermediaries ("consumerism", "user democracy") [2].

However, this view of citizens as consumers of public services and their potential to utilize the technology to exercise influence in this respect is debated. For instance, in research on electronic democracy the concept of citizens as consumers is used with a somewhat critical perspective on what this might mean

in theory as well as in practice (c.f. [7,28]). This especially applies to the view of citizens as consumers of public services supported by information technology when contrasted with the concept of citizen within representative democracy [28]. However, other authors define information technology as a resource providing citizens as consumers with capacities to enhance their position in various ways. For example, Bellamy and Taylor look upon information technology as, among other things, a means of collecting information about the preferences of citizens as well as the choices of public services made by citizens [4]. Also, from a consumerist position, Loader discusses the potential of technology to give a more direct access to welfare services [24]. Lastly, Eysenbach and Jadad define information technology as a tool to create well-informed and more actively involved healthcare consumers as opposed to passive patients [10].

In this paper we acknowledge the importance of representative democracy and associated activities and technologies as described above. This also means that we acknowledge the supplementary role of the consumerist activities and technologies [2]. Despite this, we argue that the forms of citizens' influence induced by the marketisation reforms and the new electronic intermediaries have previously only to a limited extent been discussed in a systematic manner based on factual and broad empirical experiences (c.f. [2,4,24]). We claim that as a consequence of these changes citizens are provided with certain capacities to act that should be considered and evaluated in their own right. This paper will contribute to previous research by focusing on actual experiences of the capacities provided by electronic intermediaries within healthcare and education, representing public services that are of reoccurring relevance in our daily lives.

Further, the new types of electronic intermediaries are not only initiated by public agencies [29, 32], but also by private and semi-private agencies [17,19,20,22]. Here we claim that the advent of electronic intermediaries owned by semi-private and private agencies means that citizens are provided with additional capacities as compared with those provided by publicly owned intermediaries. This means that it is important to investigate what this might mean in theory and practice. Thus by addressing the issue of ownership of electronic intermediaries our research adds a further dimension to previous discussions of consumerism and information technology [2,4,24].

In sum, the point of departure of this paper is the introduction of quasi-market arrangements and the introduction of new electronic intermediaries between citizens and the public sector. Focusing on two selected intermediaries representing different ownership the aim of the paper is to problematize the capacities to act that citizens as consumers of public services are provided with. Consequently, the most important question in the paper is: how can these capacities to act be characterised? In order to relate these capacities to the larger issue of citizens' roles in a traditional democratic system of government we will also shortly discuss how they feed into the public policy-making process in

representative democracy. In this endeavour we will employ a standard description of the policy cycle as referred by [5].

The article proceeds as follows: First there is a section where fundamental concepts in this study are further developed. Then there is a section about methodological issues in association with the study. Thereafter follows our analysis of the experiences of patients' online communities and publicly owned portals for educational opportunities. Lastly, there is a discussion about the implications of our study from the point of view of citizens as consumers and their capacities to act as well as their role within representative democracy.

BACKGROUND

The phenomenon of quasi-markets has a background in the 1970's and the renewal of the public sector, often referred to as 'New Public Management' (NPM), which in many OECD countries dominated the reform agenda. During the 1980's and 1990's this changed into a drive towards greater competition and the extensive use of contracts in public administration [4,23]. One special feature of this process was the introduction of quasi-markets for public services such as education, social services and healthcare [4,23, 29]. Leading theorists describe quasi-markets as follows:

"Thus [. . .] there are independent institutions (schools, universities, hospitals, residential homes, housing associations, private landlords) competing for customers. However, in contrast to conventional markets, all these organizations are not necessarily out to maximize their profits; nor are they necessarily privately owned". ([23], p. 10).

In different ways information technology can serve as a source of information about available options and also provide even further forms of support in quasi-markets [13,32,34]. The emergent forms of new electronic intermediaries between citizens and public sector services featured in this study are examples of technologies that might serve these purposes.

It is a relevant question to ask what characterizes these newtypes of electronic intermediaries compared with more traditional ones. First, an important aspect is that in various ways they are related to public services within some sort of quasi-market arrangement or other arrangement with mechanisms for citizens' choice between for example service providers. In contrast, e.g. websites or portals owned by public agencies often show general information about their activities [14]. Alternatively, they deliver strictly defined public services or integrate such services from several public authorities as in the case of the "one-stop-shop" concept for service provision [3,39]. This means that electronic intermediaries like these could qualify as the type of intermediaries discussed in this paper but only if they provide information about public

services within some sort of quasi-market arrangements or other arrangement for citizens' choice as described above.

Second, concerning electronic intermediaries with a more e-democratic stance like those associated with electronic petitioning and on-line discussion forums [8,26,31] they are part of traditional political processes within local and national politics. This means that they provide citizens with specified capacities to act in such circumstances, but only in their traditional roles within representative democracy as previously discussed [2,27].

Third, the new types of intermediaries might be initiated and owned by public agencies, but by other types of actors as well [17,19,20,22]. More specifically, some are implemented by semi-private, noncommercial rather than public agencies like e.g. patients' online communities [17,19] or by private actors like portals for medical or educational issues run by companies [15,35]. Other examples are when public agencies set up electronic intermediaries in order to show citizens various options in terms of healthcare resources, medical information [20] or educational opportunities [32].

In this article two types of electronic intermediaries are in focus; patients' online communities and public portals for educational opportunities. These two objects of study were selected since they provide practical experiences offering two complementary forms of ownership, which brings the opportunity to broaden our picture of this online phenomenon. Thus, in this manner we use the criteria of maximum of variation between cases as a basis for selection of cases [11]. Also, both types have connections to a quasi-markets situation or a situation where there is a certain degree of citizens' choice of services. In sum, this means that the two types of intermediaries provide experiences that are of relevance in an initial study like ours. Despite this we believe that a complete comparative analysis of the capacities provided by the two types of intermediaries would be less meaningful since the choice of objects is too limited.

In addition, the studied intermediaries represent practices from two important sectors of public services with the occurrence of quasi-market mechanisms and arrangements similar to many of the OECD countries [13,33]. Although we recognize the significant differences between segments of public services and between features of quasi-market arrangements in various countries we believe that there is a value in research that aggregates experiences in this way. In an introductory study like ours, this provides the opportunity to get an extended picture of what capacities to act that citizens are provided with. Further, we argue that our focus on Swedish experiences is of interest to a broad audience because of the prevalence of quasi-markets for education and healthcare [29,33], but also because of the broad access to the Internet among the population in this country [36].

RESEARCH SETTINGS AND METHOD

Patients' online communities

Much of the healthcare in Sweden is financed through public means, and patients have certain rights to choose from available services. However, there are differences between County Councils in the degree of patients' choice of physician or hospital. Some information about the available choices is communicated to citizens through various actors such as public authorities, traditional patient associations, and mass media. Also, an increasingly important actor in this respect is the growing number of patients' self-help communities online. These patient-managed self-help activities constitute an additional way of accessing information as well as interacting with fellow patients. However, in the Swedish and Scandinavian context the tradition of self-help is still emergent and not as strong as in the Anglo-American countries [22].

Patients' online communities are initiated and managed by individuals suffering from a disease (often chronic). In their efforts to manage their health situation they have found the information about their disease, from off-line as well as online sources, inadequate since it is not always available in their own language and not presented in a comprehensive way easily accessible to the laymen. Some patients have then started to bring information about the disease together and present it on a web page. Additionally, they have added functionalities such as an e-mail list, a discussion board, a guest book and/or a chat in order to get in contact with fellow patients. As more patients join, the online community is gradually formed. In addition, some patients have chosen the opposite strategy in creating online communities by first starting an e-mail list and subsequently developing the web pages.

The Internet pages of patients' online communities provide visitors with a variety of information about a specific disease together with a number of interactive facilities. In the present study the patients' online communities share these common characteristics though they differ with respect to the anticipated behaviour of their users. In addition, the communities represent a variety of health conditions such as multiple sclerosis, thyroid problems, fibromyalgia and whiplash injuries.

The selection of the ten patient online communities in the study was guided by the idea to examine the communities as an online phenomenon starting with observations of the community structure and performed online activities. The observations were followed by ten semi-structured interviews performed during March–May 2002 with the initiators of the communities. The interviewees had personal experiences that varied between two to seven years of starting and managing these kinds of online communities. Their roles in the communities can be characterized as designers of the web pages, coordinators of the medical information available and moderators of the ongoing discussions.

Public portals for educational opportunities

In Sweden, since the early 1990's all schools from introductory level to adult education are financed by public means, and the students are in a position to choose which one to attend. There are some, mostly geographical, restrictions that limit the choice. Some of the schools are run by municipal agencies and some by private or cooperative agencies. During recent years a few instances of public portals have been introduced to support citizens in their choice of education. Three of the most recent and innovative examples of portals of this kind are presented here. The first example is a portal for educational and career guidance designed by guidance professionals with a specific interest in information technology in general and the Internet in particular. It is owned by the agency for education at the municipality of Göteborg and the local division of The National Labor Market Board in Sweden. The second example is a portal that is owned by 13 municipalities in the west region of Sweden. It was designed by a civil servant working with the application process to secondary education directed towards students between 15–19 years of age in these municipalities. Our last example is specific functions on a portal owned by the Swedish National Agency for Education and designed by administrators at the agency. In our study empirical data from these three different portals will occur.

Sixteen interviews have been conducted with project leaders and designers of the respective portal/website. This means that the interviewees have a deep knowledge about the historical and conceptual background of the intermediaries, as well as concerning their actual forms of use. The interviews took place in September 2001–February 2002, and there was a second round of interviews in September–November 2002. The portals have also been examined through direct inspection with a special focus on their functionality.

Capturing the capacities to act

In our attempt to capture the capacities to act provided by the new types of electronic intermediaries we have been inspired by the concept of inscription from the actor-network theory (ANT) [1,6]. In this manner the concept has served as a guide to the topics or themes and the approach in our data collection [37].

Broadly speaking, ANT views e.g. information technology as evolving through a process in which different actors pursue their own interests, which they try to translate into social and technical arrangements [1,6]. An inscription [1,6] can be characterized as a form of anticipated behaviour that actors try to build into a technical artefact by means of such arrangements. With the aim to explore the capacities to act that citizens are provided with by means of the new types of electronic intermediaries, the main emphasis in the study is on what anticipated behaviours are inscribed into the technology, as well as on how this is pursued through different social and technical arrangements. Here it is important

to note that concerning the two types of electronic intermediaries represented in this study the discourse about their use has taken place during the past two to seven years. Also, as indicated above, the interviewees featuring in this study have been involved in direct interaction with the actual users of the intermediaries during the whole of this process.

In practice, this means that our interviews have treated the history of the intermediaries, their functionality and intended forms of use, as well as their actual use with a special focus on users in the general public (patients, pupils, parents, etc.). On the other hand the observations considered the general technical infrastructure along with the kind of information and interactive facilities provided.

In this way data has been collected about different forms of social arrangements such as actual situations where the intermediaries are used as well as various instructions about how they should be used. Also, the data collection resulted in an initial understanding of the technical arrangements representing the functionalities and design of the intermediaries. Thus, the social and the technical arrangements have served as a basis to describe the various capacities to act that have been inscribed into the two types of intermediaries. Apart from this, a closer examination of the actual behaviour of the users of both types of intermediaries might have been appropriate. For practical reasons this has not been a part of the present research approach in other forms than that their reactions and behaviour have been an issue in the interviews.

RESULTS

Patients' online communities in quasi-markets for healthcare

In the studied online communities the most common arrangement is to provide patients with information (Fig. 1). The basic idea is to help patients to become well-informed about the disease and increase their options in dealing with their situation as a patient and to make informed choices in the healthcare system.

The observations of the web pages show that this is emphasised in the online communities in several ways, e.g. in text on the “welcome-page” and also by the design of the community pages linking the visitor to pages about “symptoms”, “diagnosis”, “treatments”, “The disease” or to other sources of medical information on-line as well as off-line. In one of the participating communities the idea to inform was expressed as¹:

“ . . . the work in our group focuses on the collection and distribution of information about our disease. . . ”

¹ Since the empirical study was performed in Swedish all presented quotes from the interviews and the observations are translated to English by the authors.

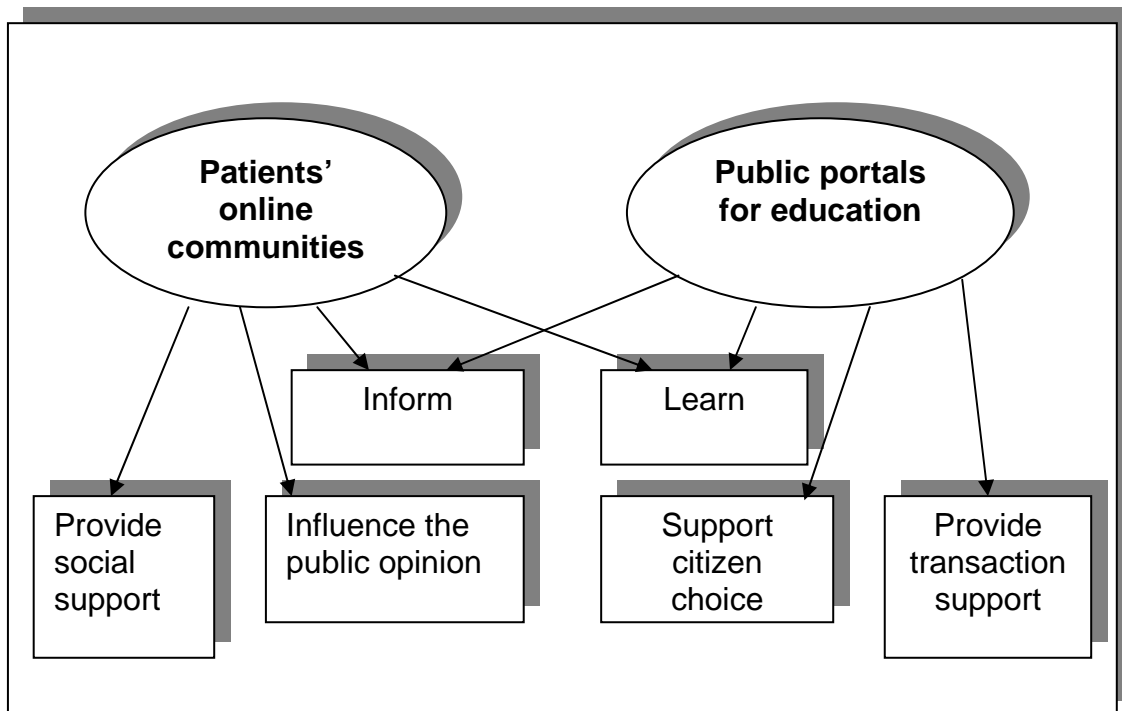


Figure 1. Capacities to act supported by the studied electronic intermediaries.

One of the interviewees also pointed out that the reason for focusing on informing others was:

“[To] help others to find the information that I earlier missed myself and I want to prevent them from making the same mistakes as I did.”

The idea to inform is for many of the online communities closely related to the aim of serving as a learning environment on the Internet. Several of the interviewed initiators of the online communities reported that when they were diagnosed they wanted to learn more about the disease in many ways.

Since they had a hard time finding information resources covering their specific disease and situation as a patient, they started their own web page in order to support other patients learning about the disease. The endeavour to serve as a learning environment is materialized e.g. in the expressed purpose of the online community emphasizing the idea of patients becoming “their own expert” and by the extensive lists of links to other sources of medical information, sometimes referred to as “recommended readings”:

“The main purpose of this web site is for you to continue to learn actively on your own and become your own expert.”

The idea to inform and to learn involves not only different kinds of medical facts. Also, the medical information of the everyday life as a patient and the need for human understanding becomes important in these online communities. This becomes clear from the arrangements of different interactive facilities (like e-mail lists and discussion boards) for creating social support. The general idea is to promote discussions and personal interaction and in this way serve as a meeting place for fellow patients. One of the interviewees described this as follows:

“Here we discuss anything that concerns what it’s like to live with this disease. We give each other both practical advice and emotional support. [...] We try to help each other with both the big and the small things in our everyday lives.”

The participants are encouraged to join the dialogue and the benefits for patients to participate are clearly pointed out on the web pages as well as in the ongoing discussions. There are also well-described technical and social instructions for how to participate.

In most online communities the focus on social support is highly emphasized while in a few the idea to serve as a means to influence the public opinion is pointed out as even more important. Since some diseases are not as well-known, several of the interviewees pointed at the need to create “disease awareness” among patients and in society in order to affect the way these patients are treated by the healthcare system. On the homepage of one of the participating online communities this was expressed as:

“[The aim is to] create a better understanding of, as well as distribute information about, this disease in society. [We would like to] try to achieve a changed attitude within the clinical healthcare.”

These issues are also the topic of much of the information available on the web pages. The user is notified when the disease has attracted attention in mass media and there are reprints of newspaper articles available. There is also information about legal cases concerning the disease. In addition, the intention to affect the public opinion becomes visible in the expressed request for patients to participate in a public discussion, online as well as offline, about the situation (social and medical) for the specific patient group.

Public portals in quasi-markets for education

The most common arrangements are those supporting that the portals might be used to obtain information about available educational options. These kind of arrangements appear in all three cases. It is communicated or inscribed by means of the links to information that are saliently located on the portals, as well as by means of instructive texts on the portals. However, the information varies in

regards to its source and format. Some information is provided through links to the different schools at various levels of the educational system, whereas other information is provided in the form of descriptions made by the public agency that owns the portal as well as links to other portals providing information on educational issues. Also, some information is provided in the form of statistics or written reports. Arrangements of a more social character also embody this type of capacity, for example in open centres where one of the portals is presented as a source to open up access to information, or in form of written instructions communicated in personal letters and in advertising campaigns.

Further, the portals might be used as a means for learning about the choice of education, which is described in the following way by one of the interviewees:

“Maybe the best way of describing the intentions is that we try to create a situation of learning. In this situation we like to provide the client with more information in order to increase his/her knowledge about what it means to make a choice.”

The further intention here is that the user should be equipped to act more independently as regards to the choice of education, as well as being capable of planning the whole educational program leading to certain goals:

“Its about increasing their consciousness, and to communicate the importance of knowing more about the world as well about oneself, in order to become capable of performing strategic choices.”

In some cases this intention is expressed by means of the easy and self-instructing structure of the portal, but also in social arrangements through the advice of human instructors in the form of guidance professionals.

Yet another type of arrangement embodies the intention that the portals might be used to support as well as to improve the actual choice of education. The most obvious example is the facility to support self-reflection about preferences and personal capacities in order to attain an enhanced choice of education. In practice, this means that a whole section of some of the intermediaries is dedicated to such facilities. Also, decision-charts in connection with the choice of education are provided. But there are also technological arrangements that could be used to compare the different educational options, for example in the following way:

“Then we have flexible League Tables by which one school could be compared with many other schools. [. . .] One of the target groups for this facility is parents in need of information when choosing a school for their children.”

A last type of arrangement support the intention that the portals might be used to carry out transactions for example in the form of the application to different schools and educational programs:

“I have focused on prospective students in the process of pursuing their actual choice of upper secondary education. [. . .] We try to be a little more persistent in the letter when talking about the potential [to register one’s choice of schools and programs] and request urgently that they should use the portal.”

This intention is communicated by means of instructions on the portal, but also through an instructional letter that is sent to all of the prospective students in the region.

DISCUSSION

The present study brings together experiences of two emergent forms of electronic intermediaries between citizens and the public sector and its services. In the previous section we have shown various capacities to act (Fig. 1) embedded in the social and technical arrangements in connection with the intermediaries. In the next section, the meanings of these capacities for citizens seen as consumers of public services will be discussed using three dimensions derived from the findings. Our way of conceptualising the capacities to act in dichotomies has been inspired by Saltman and his analysis of patient choice and patient empowerment [33]. However, this conceptualisation was held on a general level and did not include issues about the role of information technology.

As noted above, we acknowledge the supplementary role of consumerism and user democracy compared with traditional forms of influence in association with representative democracy [2]. Despite this, a relevant question to ask is how these additional types of capacities feed into the traditional public policy-making process. Therefore, in the final section we will briefly discuss these capacities in relation to the traditional role of citizens in the representative democracy.

Citizens’ capacities as consumers of public services

By means of the new types of electronic intermediaries citizens are supported in various ways. First, the intermediaries involve a dimension of citizens acting both as users and producers of information [17] and as such play different roles as actors on the public market. In the case of patients’ online communities, initiated and managed by citizens on a personal basis, they serve as a means to socially support fellow patients, to influence the public opinion, to inform, and to create a learning environment. This provides citizens with the opportunity to become informed but also to actively contribute to the content of the electronic

intermediaries e.g. by bringing together medical information from various sources and by participating in discussions.

In the case of portals for educational opportunities owned by public authorities citizens are mainly considered as users of information although with a few exceptions such as submitting and publishing questions. However, user satisfaction of the portals is continuously negotiated through various investigations of how they might be improved [18], which might in turn affect the provision of information in a long-time perspective.

In sum, this indicates that citizens as consumers of public services have a more extended role as producers of information in the semi-private patients' online communities compared with portals for educational opportunities owned by public agencies. This, in turn, is in line with the ideal of active citizenship where citizens are in a position to affect the design of the technological tools by which to exercise citizenship [9].

A second dimension involves arrangements supporting that the intermediaries might be used to learn and to inform generating capacities to act that facilitate citizens to develop specific as well as general knowledge. Through the intermediaries citizens find detailed information about e.g. diseases or medical treatments as well as information about available schools and programs of education with their respective qualities. Concerning the portals for educational opportunities this is a basis for enhancing the capacities of citizens in a concrete situation of choice of e.g. primary or secondary school. Regarding the patients' communities the specific knowledge becomes a basis for patients to develop an increased understanding of their disease related to their own specific case of illness, for example concerning the relationship between personal test results and ongoing treatments.

On the other hand, the patients' online communities involve access to broad sets of medical information on a disease like diagnosis and symptoms but also available treatments. Regarding the portals for education their users might access information on a wide scope of schools and programs, often including information about what they will lead to in terms of professional future. As such, both types of intermediaries with their respective forms of ownership support the performance of immediate actions such as various transactions or choices as well as the development of a deeper understanding about e.g. a disease during a longer period of time [19] or education in a more or less lifelong perspective [32].

Third, the identified arrangements generate capacities to act both on an individual and a collective basis [33]. The former involves enhanced capacities to e.g. pursue transactions and personal choices of public services using both specific and general knowledge as described above. However, it also involves the potential to strengthen the position of an individual citizen when interacting with professionals within respective sector of public services. More specifically, concerning the relationship between the patient/healthcare consumer and the

treating physician/clinic the patient is more often in a position to challenge the medical expertise and to negotiate his/her treatments [16]. Further, the portals for educational opportunities support the citizens' ability to act in a well-informed and competent way independently of e.g. guidance professionals that usually play a significant role in the choice of education. In fact, some authors argue that in these and similar circumstances the aim of introducing technology to provide information and other forms of support is in line with the larger intention to accomplish a more independent agency from the side of citizens/clients [30,38]. This is not to say that the relationship between citizens and professionals by means of the electronic intermediaries is changed into one among equals. Instead, the larger issue of power in the relationship between government and citizens mediated by information technology is relevant and calls for a deeper future analysis [12].

On the other hand, the collective dimension is related to the activities with the intention to socially support others and to influence the public opinion in the semi-private patients' online communities. Here fellow patients get in contact with each other, and messages about how to act and what to demand from healthcare is spread through the community. An example is when a patient is treated with a new and perhaps controversial treatment. His or her experiences discussed in the online communities might affect also what many other patients will ask for or refuse. Another example is patients' collaborative efforts in creating "disease awareness" making a disease known by such efforts as participating in a public debate off-line and online about e.g. the specific conditions for a patient group and how they are treated by healthcare providers/professionals.

In sum, the capacities to act generated by the intermediaries involve the view of citizens as consumers taking all sorts of action. Further, some authors argue that the idea of providing citizens with the potential to influence their choice of public services might be considered to be contradictory to the idea of influencing public services by means of any form of collective action [4]. As a contrast, since individualistic as well as collectivistic aspects are enhanced through the new electronic intermediaries, in practice they might be characterized as deeply intertwined. This means that we argue along the same lines as Saltman and his observations regarding the competent exercise of patients' choice in healthcare:

"In effect, competent patients like sagacious citizens are made not born. In taking the distinction between economic and political notions to this level, one can argue that [. . .] patient choice – properly construed and introduced in a correctly constructed environment could be a mechanism to educate citizens into greater participation in society and responsibility for their fellows."([33], pp. 207–208)

This implies that the electronic intermediaries generate capacities to act that enable citizens to put new and additional demands on the public service provided not only from a personal point of view but also from a more general and collectivistic.

Citizens' capacities and the policy cycle

In a standard description of the Policy Cycle within e.g. national and local government politics referred by Beynon-Davies et al. [5] Policy Initiation is performed by political bodies taking both political demands from the environment and resources available into account. Thereafter, in the Policy Formulation the suggested policy is modified and subsequently ratified. During the Policy Execution various forms of public service are delivered followed by the Policy Consultation where both partner organisations and citizenry can hand in their views on e.g. the service produced. The latter activity might result in re-formulation of policies.

At a general level, we have shown that both types of electronic intermediaries with their respective qualities and forms of ownership improve the knowledge about public services among citizens. In deliberative processes for example in local government [5,31] in association with e.g. Policy Initiation and Policy Formulation this knowledge is a relevant resource for citizens, that otherwise might suffer from a deficit in knowledge [21] compared with politicians and civil servants working with these issues on a daily basis. This is an especially important aspect concerning education and healthcare, we argue, because these sectors represent a large and therefore important part of the public services available to citizens.

In contrast, concerning the more collective forms of capacities to act induced by e.g. patients' online communities the situation is somewhat different. The capacities to influence the public opinion and the facilities to create social support among fellow patients are both similar to more traditional forms of activities in political associations and parties. However, the activities in patients' online communities and the like can be characterized as highly interest-based [25] and therefore less broad in scope compared with traditional political parties. Despite this, in terms of the Policy Cycle [5] activities like these can be part of the demands from the environment that is fed into the Policy Initiation stage, thus preceding Policy Formulation.

Also, in situations where there are quasi-market or similar forms of arrangements for citizens' choice the very choice itself can be characterized as a form of Policy Consultation where the views of the citizenry play a prominent role. In circumstances like these the input from the citizenry might be of a very direct character in the form of the actual choice between available suppliers of services. In this manner, the decision about the exact distribution among service providers is more or less, depending on differences as regards the institutional arrangements [23,29], taken by the citizens themselves. More specifically,

mechanisms for citizens' direct choice of services might be characterized as a way of bypassing the decision about the framework for service provision that are taken in the traditional democratic process ("Policy Formulation"). However, in this respect the marketisation arrangements are the most important precondition since they provide the framework for citizens' activities irrespective of the emergence of new types of technologies.

CONCLUSION

The purpose of this study has been to problematize the capacities to act that citizens are provided with by means of new types of electronic intermediaries between themselves and the public services with a special reference to a quasi-market situation [23]. The identified capacities to act is characterised as means for citizens to use and produce information, to develop specific and general knowledge, as well as to act on an individual and a collective basis. We conclude that the intermediaries are sophisticated instruments in a learning process that support the citizens' development into active consumers of public services.

The present study considers practical experiences from two selected types of electronic intermediaries representing both public and semi-private forms of ownership. Our hope is that the presented experiences will serve as a first step in a more complete analysis of the implications of electronic intermediaries for the capacities of citizens to act as well as for the public sector itself.

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