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

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## 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.*

*Keywords: Internet, E-health, E-patients, information use environment, personalization, user context*

# 1 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.

## 2 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	<input type="checkbox"/> Diabetes <input type="checkbox"/> Hearing disorders <input type="checkbox"/> Psoriasis <input type="checkbox"/> Parkinson disease	<input type="checkbox"/> Tourette syndrome <input type="checkbox"/> Whiplash injury <input type="checkbox"/> 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	<input type="checkbox"/> Whiplash injury <input type="checkbox"/> Polycystic Ovarian Syndrome (PCO) <input type="checkbox"/> Endometriosis <input type="checkbox"/> Multiple sclerosis (MS)	<input type="checkbox"/> Chronic Fatigue Syndrome <input type="checkbox"/> Chronic prostatitis <input type="checkbox"/> Fibromyalgia <input type="checkbox"/> Panic disorder <input type="checkbox"/> 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.

### 3 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.

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

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

## 4 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.

### 4.1 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”.

#### **4.2 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 know 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).

#### **4.3 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”*.

#### **4.4 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.”*

<b>Problem</b>	<b>People</b>	<b>Setting</b>	<b>Problem resolution</b>
Diagnosis and related characteristics (stages, phases, treatments, side-effects, etc): <input type="checkbox"/> Severe fatal disease <input type="checkbox"/> Chronic life long disease <input type="checkbox"/> Stigmatising disease <input type="checkbox"/> "Less know"/-"difficult-to-decide" disease <input type="checkbox"/> Disease involving relatives as main caregivers	<input type="checkbox"/> Special interest group <input type="checkbox"/> Age <input type="checkbox"/> Sex <input type="checkbox"/> Education <input type="checkbox"/> Preferences and attitudes of <input type="checkbox"/> Internet use in the patient – healthcare relationship	<input type="checkbox"/> Values and attitudes related to the changing patient role <input type="checkbox"/> Personal interest – group interest <input type="checkbox"/> Physical access and personal sources <input type="checkbox"/> Knowledge and experiences of seeking and judging online medical information	<input type="checkbox"/> Seeking online medical information <input type="checkbox"/> Seeking social support <input type="checkbox"/> Facilitating others

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

## 5 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.

### 5.1 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 point 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 *complimentary* 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.

## 6 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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