Patient's Use of Medical Information on the Internet: Opportunities and Challenges

Some preliminary findings

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Abstract

This article presents some preliminary findings concerning patient’s use of the Internet for medical information. The aim is to increase our understanding of patient’s on-line activities using the perspective of Virtual Communities. The study reported takes the point of departure in Internet use by patient associations and their contact with patients. This approach provides an opportunity to analyse a larger and more varying group of patients and their use of the Internet for medical information. The results of the study points at a number of opportunities and challenges both for patients as individuals but also for health care providers and society in a larger perspective.

Keywords: Patients, Medical Information, Internet, Virtual Communities

1. Introduction

As a source for medical information the Internet is no longer a concern only for health care professionals. The number of people who can access the information is growing and so is the amount of information available (Coiera, 1996). This means new opportunities for patients to become well informed and to take an active part in their own treatment process. However, patients use of the Internet also means many challenges e.g. concerning the quality of the information available and the relationship between patients and health care providers.

Earlier research conducted have focused areas like the use of interactive facilities by specific groups of patients (Smith, 1998; Feenberg et al, 1996; Hoch et al, 1999), the quality of the medical information on the Internet (Coiera, 1996; Shepperd et al, 1999) and the relationship between patient and doctor due to the use of the Internet (Hjortdahl, 1997, 1998; Hjortdahl et al, 1999, Coiera, 1996). Most of these studies have the perspective of health care providers or a particular group of patients or the medical information intrinsically. The study reported in this article use a somewhat different approach by taking the point of departure in Internet use by patient associations and their contact with patients. This provides an opportunity to analyse a larger and more varying group of patients and their use of the Internet. In addition, to further the discussion the concept of Virtual Community is applied.
According to Stolterman et al (1997), it is important to study virtual communities of several reasons. First, it is time-consuming to develop a research area meaning that many studies conducted so far have not being deep enough. Second, since cyberspace and the Internet are evolving many questions of how this influence the society becomes important. Third, also the society is dynamic and changing and since virtual communities are part of the changing society, they are important to study. Finally, Stolterman et al (ibid.) points at the fact that additional studies will increase the knowledge and understanding of virtual communities, which is necessary to make them further develop.

In this article the concept is applied in a wide sense following Wellman & Gulias (1999) and Stolterman et al (1997) idea of Virtual Community as being a social entity not separable from the rest of society. In this article the term is used in order to describe the characteristics of patient's on-line activities. Applying the concept also makes it possible to further our knowledge of the complex social pattern in which these on-line activities are a part. Further, it supports an increased understanding of the opportunities and challenges for both individuals and society that lies within patient's use of the Internet for medical information.

It should also be pointed out that the term "medical information" in this article is recognised in a wide sense, meaning all the information on the Internet that patients can use in order to influence their situation as patients.

The aim of the article is to increase the understanding of patient's use of the Internet for medical information. In addition, the aim is to contribute to the knowledge base of virtual communities and their impact on society in a larger perspective.

Consequently, the main questions of the article are; what opportunities and challenges can be identified in patient's use of the Internet for medical information? What are the implications of patient's use of the Internet for patients, health care providers and the society in a larger perspective?

The study reported focuses on the Internet use by patient associations and their contact with patients. During February and March 2000, interviews with patient association's representatives were conducted where each association represents a specific group of patients. This approach provided an opportunity to analyse a large and varying group of patients and their use of the Internet. It is the preliminary findings of this study that are reported in this article.

2. Existing research on patient’s use of the Internet

The results of earlier research in the field indicate that patients increasingly are turning to the Internet for various medical information (Shepperd et al, 1999). However, a main issue is the fact that there is a lot of misleading information of low quality available. This is pointed out as one of the weaknesses of Internet when it comes to patient's use (Pereira & Bruera, 1998) and it is contributing to patients becoming misinformed instead of well informed.

Patient's requirement for access to reliable information sources on the Internet is discussed in a study by Shepperd et al (1999). The need for health professionals to have reliable Internet sources to guide their patients to is also pointed out. These requirements are denoted as core issues when it comes to patient's opportunities to take active part in decisions concerning their health care situation. However, the interpretation and retrieving of medical information is found difficult. The reasons are to be found both in the fact that the quality of the medical information available is varying and the quantity of
medical information is constantly increasing on the Internet. The fact that the Internet is dynamic and constantly changing further complicates the picture.

Another research area concerns the relationship between patients and doctors due to the use of new information technology. Patient’s access to medical information on the Internet means new challenges for this relationship (Hjortdahl, 1997; Hjortdahl, 1998; Coiera, 1996). In a study by Hjortdahl et al (1999) it was found that well informed patients are becoming parts of the everyday clinical life of doctors. The results of the study shows that as much as 74% of the participating doctors have experiences from meetings with patients bringing information from the Internet.

There is a trend toward patients more frequently taking active part and responsibility in their own treatment process. This is being expressed as patients going from saying, “Tank you” to asking “Why”? The reason for this is to be found in the relationship between the development of society and new technology use (Hjortdahl et al, ibid.).

An additional factor likely to have great impact on the relationship between patients and doctors studied by Hjortdahl et al (ibid.) concerns the use of Internet as a tool not only for information access but also for communication. The use of e-mail among doctors was studied and the results indicate that only a few doctors provide their patients with the possibility of e-mail contact despite a high interest from the patients. Coming to the same conclusions this issue is also discussed by Pal (1999). In both studies several factors are discussed analysing the reasons for this situation e.g. fear of increasing workload, uncertainty concerning confidentiality, economics and computer safety.

The potentials of the Internet for communication and interaction between patients are another subject for research concerning patient's use of the Internet. Several studies reports how patients using the Internet for communication and interaction with others can improve the control over their own medical care and at the same time help others (Smith, 1998; Feenberg et al, 1996; Hoch et al, 1999).

In the work by Hoch et al (1999), a "Webforum" is studied from the perspective of who use it, the type of information being exchanged, the amount of misinformation and how the health care providers can serve their patients better using this forum. Some unwillingness among health care providers to give information was found. However, the forum was also discovered as bringing only smaller amount of misinformation to the participants and that that the web can serve as an effective tool for the exchange of knowledge and experiences among patients.

In the study by Feenberg, et al (1996) a somewhat different approach is taken discussing on-line patient meetings from the point of social support for health. The result points at the potential of these on-line activities to further change the patient role. The authors sees the potentials of the on-line patient meetings as a possibility for patients to form networking groups that can put pressure on health care providers and politicians in order to increase their possibility to effect their own medical care.

Smith (1998) takes a more individual perspective reporting on the benefit of single patients using on-line support groups for the transfer of knowledge and experiences among patients. In this study it is pointed out that on-line support groups increases patient's possibilities to become informed concerning e.g. diagnosis, treatment and recovery.

The study reported in this article involves patients’ use of interactive facilities on the Internet. However, by taking the point of departure in Internet use by patient associations and their contact with patients the approach is somewhat different from the above-presented studies. This different approach provides an opportunity to analyse a
larger and more varying group of patients and their use of the Internet. This study also aims at analysing the influence on health care providers and society in a larger perspective due to this new technology use. In addition, to further the discussion of patient's use of the Internet the concept of virtual community is applied. Hence, in the next section this concept and the understanding of it in this article is presented.

3. Virtual Communities

It is difficult to find clear definitions of terms like "virtual" and "community" (Fernback, 1999) and several ways to look at them exists. When brought together the task of definition does not become an easier effort. This is further complicated by the fact that the technology involved is dynamic and constantly changing (Stolterman et al, 1997). However, in this article the concept will be used in a wide sense influenced by the descriptions and discussions of Virtual Community presented by Wellman & Gulia (1999) and Stolterman et al (1997).

According to Stolterman et al, (ibid.) a virtual community is pictured as a "social entity" meaning that it is a part of society and can not be considered separately. Practically it is "a group of people who relate to one another by the use of a specific technology"(p 2).

This description of the concept relates very well to Wellman & Gulias (1999) picture of virtual communities as Computer Supported Social Networks (CSSN) which can not be treated isolated from other aspects of people's social lives.

When examining research findings with contemporary experiences of virtual communities, Wellman & Gulia (ibid.) point at several characteristics of individuals' online activities and relationships.

First, on-line relationships are specialised where people turn to different virtual communities for different kind of support. This means that "people must maintain differentiated portfolios of ties to obtain a wide variety of resources" (p 171).

Second, on-line relationships and activities do not focus on people's social status, which can be of advantage for individuals with a lower social position. The relationships in virtual communities are instead more concentrated to people's shared interests. However, this means that new forms of homogeneity may develop.

"Despite the medium's potential to connect diverse cultures and ideas, we suspect that people are generally drawn to electronic groups that link them with others sharing common interests or concerns" (Wellman & Gulia 1999:185).

Third, on-line relationships are supportive. People tend to help and support each other although this sometimes means turning to complete strangers.

Fourth, also strong and deep relationships are possible on-line albeit there are many threats e.g. technological shortcomings and unfaithful on-line behaviour.

Finally, on-line relationships and activities can be viewed as a complement to off-line contacts. People do not consider off-line and on-line activities as separable since many contacts involve both.

"Just as community ties that began in-person can be sustained through e-mail, online ties can be reinforced and broadened through in-person meetings (...) By supporting on-line contact, the Net may even foster more frequent in-person meetings between persons who might otherwise tend to forget about each other ". (Wellman & Gulia 1999:182,186)

Wellman & Gulia close their examination of the virtual community concept by
concluding that as the same time as virtual communities move some of the social interaction from the off-line arenas it also serves to integrate society. This means that virtual community brings different kind of people together who would otherwise never have met.

Given these aspects of virtual communities the concept in this article is treated as a space on the Internet where people supported by new information technology participate in various on-line activities. The on-line relationships are based on a common interest – in this case different diseases or disablement. In addition, virtual communities are recognised as an integrated part of society meaning that what occurs in these communities is also reflected in "real-life" society.

4. The study

Medical information of different kind is available on the Internet. According to what has been presented from earlier research this fact is an important issue to study also from the patients' point of view. The overall purpose of the study reported in this article is to present an overview of patient's use of the Internet for medical information. In addition, the aim is to create a basis for further studies in this research area. In order to accomplish this an initial study was performed in order to understand more about the activities taking place.

4.1. Material

The ambition to perform a study of this kind also involves the ambition to search for a broad empirical basis. In this case, patients as a group of individuals are difficult to access since being a patient very much concerns people's integrity and private lives. Hence, in this study the point of departure is Internet use by patient associations and their contact with patients. This approach was chosen in order to analyse the on-line activities of a larger and varying group of patients. Further, when analysing patient's use of the Internet for medical information these associations are important actors providing arenas and spaces for patient's on-line activities. They also constitute a basis for further development of intermediary institutions for patient's use of the Internet.

The patient associations participating in the study can be characterised as organisations with the aim to support people suffering from a specific disease or disablement. The support concerns medical or health care issues as well as other questions concerning the patient's situation in society.

4.1.1. Patient associations

Patient associations can be described as non-profit organisations that with a broad perspective work to improve the conditions for patients in society. This means active interest towards not only health care but also society in a larger perspective. The associations work a lot with providing their members with different kind of information concerning e.g. diseases, medicines, methods of treatment etc. They also provide information about means of assistance, how to act towards authorities and insurance companies etc.

Further, the patient associations work to influence the public opinion in order to improve patient's conditions. These activities are performed through e.g. calls on
politicians and authorities and through publicising various articles.

The associations are different when it comes to the number of members but also concerning their financial basis. Some of the largest associations have about 50,000 members while the smaller have 2,500 members. The larger associations are receiving grants for some of their work while the smaller are completely dependent on voluntary work.

The groups of patients involved in the associations are also varying. Some are suffering from diseases quite common in society e.g. diabetes and they share their experience with many. Other groups of patients have diseases or disablement less frequent like e.g. Tourette’s syndrome. This fact of course effects the number of members and the size of the patient associations but also the financial basis and the ability to improve their members’ situation.

4.2. Method

With the objective to understand more about patient's use of the Internet and their on-line activities the interactive facilities provided by the associations is important. It is important to find out what, how and where the activities are occurring. Consequently, focusing interactive Internet facilities provided at home pages of the associations 7 of them was contacted with a request to participate in the study. The participating associations were selected from four lists on the Internet containing Swedish patient associations. Each of the associations represents a specific group of patients.

The study was conducted during February and March 2000 and the empirical data was collected through semi-structured interviews with representatives from Swedish patient associations.

After an initial telephone contact with the patient associations, five of the interviews were conducted over telephone and two using e-mail. The telephone interviews lasted for about 30-40 minutes each. Notes were taking during the interviews and later put together for the analysis. The "mail-interviews" were performed by sending the questions by mail to the contact person who answered them within two weeks. The answers were returned also using mail.

The persons interviewed had different tasks at the patient associations. Some were web masters and/or involved in the presentation of the association's information in different respects. Several of the interviewees also had personal experience of the diseases or disablement that the association was working with. This means that they had the experience of being patients using the Internet for medical information.

During the interviews, the introductory areas covered the initiation and purpose of the Internet pages. Other questions concerned interactivity communication and patient's need for medical information. The purpose was to find out e.g. what the patient associations wants to achieve by providing these facilities, how they are used and how they have evolved over time. During the interviews the future strategy for the patient association's use of the Internet was also discussed An additional field of question related to the use of Internet with the purpose to influence the public opinion.

4.3. Findings

The results of the study found patients need for medical information extensive. In some cases, this need has even contributed to the initiation of patient associations. However, the need for medical information is very complex and from the results of the study, it is
possible to distinguish four main characteristics of the required information. First, these information characteristics are presented. This is followed by results pointing at the importance of the interactive facilities and Internet spaces provided by the patient's associations. The section is then closed by findings concerning the patient association's use of the Internet.

4.3.1. Characteristics of patient's need for medical information

First, it is important to understand that patients have very different need for medical information. "Patients" must be recognised as a heterogeneous group of individuals all having their particular interests and need for information. For example, some of the participating patient associations have members having diseases that mainly elderly people suffers from. Other associations represent patients in different ages, children as well as adults.

The patients need information about many different aspects of their medical care. Their requirements for medical information concern e.g. the picture of a disease and existing methods of treatment. They also want to know about possible complications and about medicines and their sideeffect. Other questions might concern existing means of assistance as well as how to act towards different authorities. It is also important to understand that suffering from a disease or a disablement also involves patients being at different stages and thus needing medical information adjusted to their specific situation.

Second, it is important for patients to have access to medical information of high quality. The interviewees reported that unfortunately there is a lot of misleading information available on the Internet e.g. concerning medicines and treatments. The interviewees gave some examples of patients finding information about different kind of miraculous treatments for diseases that are recognised as incurable or chronic.

Third, the information must also be available in an easy accessible manner meaning that the information must be presented in the patient's language and in a way understandable also for layman. Sometimes the information available is accessible only in foreign languages and directed toward persons with high level of medical knowledge. Some of the interviewed representatives pointed at this as a core issue for their association and for patients. The associations spend a lot of resources trying to get the information quality ensured and to translate the information and present it in a way readable also for laymen.

Fourth, patients need to share their experiences with each other. Several of the interviewees reported of patients expressing their need to communicate their experiences with other people sharing their situation. This means that patient's use of the Internet for medical information not only includes information provided by health care professionals but also patients sharing their personal experiences and knowledge. However, these activities require virtual spaces on the Internet and patient associations provide some of these through various interactive facilities.

4.3.2. The interactive facilities

In the study the objectives concerning the interactive facilities provided by the patient associations was pictured as a possibility for patients to contact each other and to share their experiences. The purpose was also to get patients more engaged in mutual interests shared by the specific group of patients. This provides an opportunity to form stronger associations with greater impact on the society in different respects. However, during the study it was pointed out that it is still a rather small group of patients that use or can use
the Internet for medical information, although this group of people is growing in numbers.

The results of the study show that the interactive and communicative facilities supplied by the patient associations are frequently used. Most of the associations provided "Discussions", "Chats" and/or "Guestbooks". These interactive facilities can be pictured as spaces used for contact and support between patients. Several of the interviewees reported of patients expressing the benefits of these interactive tools for the exchange of knowledge and experiences. Patients have pointed at a considerable need for these kinds of forums e.g. when being diagnosed and many questions need to be answered also after leaving the doctor. The need for these spaces was also pictured as important for patients just needing someone to talk to or as "a place" to go to for support and understanding in a difficult situation.

Most of the participating patient associations also have Internet facilities for ordering information such as brochures books, posters, videos etc. These interactive tools are not only used by patients but also by e.g. health care professionals working with patient information in different respects.

The ongoing process of development of the interactive tools is characterised by the interviewees as increasing and broadening. The number of people participating in the discussions is increasing and the subjects of discussion are wider now than in the beginning. The participants do not only discuss the specific diseases or disablement but also other topics concerning the patient's situation in society. For instance, patients give each other advice on how to act towards different authorities in society in order to demand their rights as patients.

4.3.3. The patient associations

A part from issues concerning patient's need for medical information and their use of interactive facilities the interviewees was asked question concerning the patient association's use of the Internet. The answers describe the purpose of the use of Internet and the hopes of the future of this development as well as some of the problems the associations are facing.

By their activities on the Internet, patient associations want to reach large groups of people with their information. They want to be seen both for patients and members but also for health care and the rest of the society. Further, they want to act as a "search engine" of relevant information for their members. An additional purpose of their activities on the Internet is the ability to reach new potential members and to get more members active and informed about health care, treatments, research, politics etc.

Another purpose is to make patients take an active part and through this make the association stronger, and improve their possibility to influence the public opinion.

The interviewed representatives were also asked about the patient associations future activities on the Internet. The answers point at an increasing development and use of the interactive facilities. For example, they want to use the technology further in order to provide patients, relatives, health care professional and the public with adjusted information. This means that the Internet sites of the associations will provide specifically designed health care information depending on who the visitor is. However, when it comes to the ability to provide information the need for correct and quality ensured information is strongly pointed out.

Other ideas of how to use the Internet technology concerned the possibility to support and advice their members by helping them to find reliable services on the Internet
that could improve the everyday lives of patients.

The interviewees all pointed at many opportunities involved with the use of the Internet. However, the associations are facing several problems and the most difficult one concerns the economic resources. The ambition to develop their use of the Internet is high but the economic resources do not allow them to perform this in the way they want to.

When discussing the economic resources it was also stressed that, the use of the Internet also concerns the member's economic abilities to participate. For many members this concerns buying expensive computer technology and to have costly Internet connections etc. Some of the larger associations expressed a future possibility to provide their members with computers at their local or district offices.

Some of the interviewees also pointed out that in order to support and help patients in the best way the associations must have a working organisational structure. This means that there has to be active local associations and a strong central organisation with a distinctive image. Poor financial basis of course effects the possibility to create these necessary conditions. Some of the smaller associations have chosen to associate with other in order to improve their economic conditions. This means that the associations need each other for the resources but it can be difficult to hold together many different interests and this might lead to conflicts.

An additional challenge put forward by representatives of smaller associations concerns the fact that there is an existing competition between some associations organising patients with the same diseases or disablement. The critique concerned the risk that the membership fee is not used by the associations to improve the member's situation but instead for other purposes. This means that there is a risk that the individuals only become a name in a membership record.

5. Patient's use of the Internet for medical information

Patient's on-line activities can be discussed in terms of virtual communities. The forming of and participation in these virtual communities involves several opportunities challenges and implications both for patients and health care providers but also for society in a larger perspective.

5.1. Opportunities

The virtual communities of patients are communities of shared interests concerning diseases or disablement. Many of the activities performed in the communities involve active use of the interactive facilities available like "Chats", "Discussion", e-mail etc. The interactive and communicative facilities serve as a space for contact between patients and play a central role in the forming of patient's virtual communities with medical interests. In these communities patients can meet and discuss their health care situation and they can share their knowledge and experiences. The possibility to communicate with other people in the same situation is a central benefit of patient's use of the Internet. Suffering from a disease or disablement often involves a need to discuss the situation with others and since health care only have limited resources to satisfy this need the participation in a virtual community can be a most valuable resource. Further, for patients participating in virtual communities, the use of the Internet means help and support concerning not only specific diseases but also contact with health care providers and authorities of different
It is also important for patients to access medical information of high quality. This means that patients in order to use the information available in the best manner also must find ways to interpret and decide if the information is correct or not. If a patient do not have professional medical knowledge, this is not an easy task. However, for this purpose participation in a virtual community can be supportive and increase patient's possibilities to avoid some of the most misleading sources of medical information on the Internet.

Using the Internet patients can access the information and get answers to questions at any time. Their possibility to influence and to take active part in their treatment process increases. Further, the Internet can be used in order to get information as well as consultation with other doctors all over the world. This means that patients can learn more about different treatments, put them against each other and evaluate these when discussing these matters with their physician. Medical information on the Internet also brings the opportunity for patients to consult several doctors all over the world at the same time. The gathered information can then be used in order to get a second opinion and to have more information when meeting with their personal doctor. This use of medical information on the Internet also means that patient's freedom of choice increases since the patient can collect put together and evaluate information concerning their personal health care situation.

The access to medical information and the possibility to create patient networks also bring the opportunity to create strong and supportive associations as well as a chance to influence the society.

5.2. Challenges

Patients forming virtual communities and their use of the Internet for medical information also involve a number of challenges.

First, there are only a small group of patients who have access to the Internet and an even smaller group who have the knowledge and the resources necessary to find relevant and correct medical information on the Internet. This means that many patients can not take an active part in the development process of patient's virtual communities.

Second, as was earlier pointed out it is most important that patients get access to quality secured information. The challenge involved concerns how the quality can be ensured and how the patients can protect themselves or to be protected against the misinformation available. Several attempts have been conducted and many are still ongoing to guarantee the quality of the information but a lot of work is still needed. Since the Internet is a dynamic medium constantly changing, the task is difficult. A site can contain correct information one day and the next day not.

On the Internet, there also exist a conflict of interest that might be difficult for patients to interpret. Business interests, as commercials can often be mistaken for impartial medical information. For instance, the pharmaceutical industry sometimes is interested in patients demanding more expensive medicines form their doctors. Therefore, it can be difficult for patients to judge the purpose and meaning of this kind of information.

Third, a lot of the medical information on the Internet is directed towards health care professionals and is often produced with specific academic characteristics e.g. in the form of scientific articles or statistics in complex databases. Much of the information is also available only in the English language. Since the information is not presented in a
way understandable, also for layman this becomes a source for patients misunderstanding or misinterpreting the information.

Finally, other challenges for patients use of the Internet concerns the legal issues existing in the relation between patient and doctor using the Internet. For example, the question of responsibility is unclear if a doctor make a diagnosis wrong or if a patient understand a message or medical advise from a doctor incorrectly.

5.3. **Implications**

The patient's use of the Internet for medical information and the forming of virtual communities mean several implications for patients, health care providers and the society.

5.3.1. **The patient role**

The opportunities and challenges of patient's use of the Internet for medical information discussed here is related to the development process of a new patient role in society. This new role means that patients are expected to take an increasing responsibility for their own health care. This means that they are expected to be more active and demanding health care consumers and not only passive receivers of health care.

Patient's use of the Internet for medical information will influence the development of a new patient role in different respects. First, the access to medical information will influence the relationship between patient and doctor e.g. by patients becoming well informed. Patient's ability to put several doctors' medical opinions against each other is also likely to effect the relationship. However, the health care organisation and the medical profession are badly prepared for the effects of this development of information technology use (Jadad, 1999; Coiera, 1996).

Second, health care providers will find patients putting new demands on their own treatment process. As patients through the involvement in virtual communities will increase their medical knowledge, they will demand to decide on treatment options available (Coiera, 1996). The new possibility to access medical information that earlier was available only for health care now gives patients the possibility to become active, increase their power, responsibility and control.

Third, patient's use of the Internet for medical information will also increase their freedom of choice. For example, patients will have more information about different treatments and which hospitals or clinics provides these and how long the waiting list is. Since the Internet is world wide patients will be able to access information about treatments also in foreign countries which further increase the scope of the freedom of choice.

5.3.2. **Health care and society**

Patient's use of the Internet for medical information will effect the structures in health care. The power is moving from health care and the medical doctor to the patient. Through the access of medical information, patients can now build a base of information and knowledge that earlier was not possible. This means that the power of patients and their freedom of choice increases and that this will put pressure on the competition in health care. Patients will not be satisfied with the health care provided at their hospital if they know that a better care program is provided at other hospitals. However, patient's expectations will perhaps conflict with the health care resources available in the society.
For instance, some treatments are perhaps costly and used only in very specific cases while other might be available only in certain districts of the country or in the world.

The ability to contact others through the Internet also generates new conditions for collaboration where patients can take an active part in different kind of activities with the purpose to influence the public opinion. This means that patient's virtual communities will have effects also "outside" the Internet.

In addition, the role as a doctor is going through a change process. Just as the patient role, this is affected by patient's use of the Internet for medical information. From being a medical authority the role as a doctor is developing towards a health care professional more aware of patient's specific demands. The doctors must increasingly manage patient's requirements and have respect for the knowledge they bring of their diseases and health conditions.

An additional effect on society and health care implied by patient's use of the Internet is the need to bring the results of scientific medical research in to health care practice more quickly. Since patients on the Internet will find the latest results of medical research, they will also demand health care to utilise them.

5.4. The intermediary role of patient associations

In order to manage the opportunities, challenges, and implications involved in patient's use of the Internet and to get the potential benefit out of the technology use supportive activities and strategies become important. One such strategy involves the establishment of supportive institutions providing arenas and spaces on the Internet. These institutions should support different kind of patients finding relevant quality ensured medical information on the Internet. They should also be able to help patients who do not have a computer or that can not use the computer for this purpose. The institutions should also be able to support the interpretation and translation of the information found.

Patient associations of different kind could constitute these supportive institutions. They could help patients through putting up web pages with relevant medical information and support them in the search for information. They can also hire doctors to help with the interpretation and translation of the information and to perform other activities in order to secure the medical quality of the information.

The patient associations could also help through the establishment of groups, like e.g. news groups for the purpose of patient's communication where the patients can help and support each other. The associations should also be able to help new patients to get in contact with the electronic groups and discussion groups.

The patients associations already perform many of these activities today and the development of the use of the Internet is an ongoing process. However, an obvious problem for many of the patient associations is the limited economic resources to develop these services to their patients and members. For some patient associations, a poor organisational structure and existing parallel associations competing for members and their fees also means difficulties to provide this technological support.

It can be concluded that the virtual communities of patients and their on-line activities will have a great impact on both the patients’ individual situations and on the society and health care. This development is a dynamic change process and in order to have as many patients as possible involved the establishment of supportive activities becomes important.

For the future, many important questions are raised about the development of patient's use of the Internet for medical information. However, the change process has
just begun and as it moves on the importance of bringing patient's view to focus is increasingly important. As earlier discussed there is still a limited group of patients having access to the Internet and the opportunities challenges and implications are of course affected by this fact. However, as the development of patient's use of the Internet and their forming of virtual communities with medical interests a question put forward by Coiera (1996:3) becomes pivotal:

"Will people who have an almost unlimited access to information but limited access to health care resources tolerate suboptimal care?"

5.5. Future research

With the purpose to present an overview, this study has only briefly touched upon the research field of patient's use of the Internet. However, several areas for further studies have been recognised.

One such area concerns the relationship between patients and doctors due to the use of e-mail. Important questions to analyse are; how can e-mail be a complement to the physical meeting between patient and doctor? What are the benefits and the costs? How is the patient-doctor relationship affected? Further studies of the relationship between doctors and patients should also involve questions of how frequent doctors meet Internet informed patients.

Other future studies can be directed towards patient's use of Internet facilities to interact with each other. What are the characteristics of patient's on-line activities? What characterises the activities in "Discussions", "Chats" or "Guestbooks"?

Future research on patients forming virtual communities is also required as the interactive on-line activities are increasing and broadening. The dynamic nature of the Internet also calls for further studies concerning these issues. The impact of patient's virtual communities on both individual and societal level also require additional research concerning its "implications for the future of medical practice" (Coiera, 1996:5).

An additional area for future research should concern the quality of the medical information available on the Internet. A central issue concerns how the information quality can be ensured and how a simple access to medical information on the Internet can be arranged for different groups of patients.

6. Concluding remarks

Patient's requirements for medical information constitute specific shared interests, which brings people together on the Internet forming virtual communities. The on-line activities of patients involve both the access to medical information as well as the exchange of knowledge and experiences between patients. This development of new technology use bring a number of opportunities and challenges both for patients as individual but also implications for health care providers and society in a larger perspective. In order to get the potential benefit out of the technology the establishment of supportive institutions becomes important and in this, process patient associations are central actors. However, as a research area, patient's use of the Internet for medical information needs to be studied further and new innovative research is demanded for bringing the perspective of patients to the focus.
7. References

Fernback, J. (1999) There is a There There. In Steven Jones (eds) Doing Internet Research, Sage Publications, USA.