Patients' Online Communities

Experiences of emergent Swedish self-help on the Internet

Ulrika Josefsson

Department of Informatics, Göteborg University, Sweden

ulrika@informatik.gu.se

Abstract. This paper identifies and analyses characteristics of Patients' Online Communities (POC) in Sweden. The purpose of the paper is to increase our understanding of how individuals design online social support and how this can inform design in a wider perspective. The study presents a fine-grained picture of POC covering both the contextual structures and the community culture. Two important driving forces of POC (to get informed and to interact with others in similar situation) are identified. These serve as a basis for the introductory discussion provided on how the experiences from POC can serve as implications for the emergent design of Internet based communication between patients and health care providers.

Introduction

Today many people are involved in various online communities such as web chats (Sveningsson, 2001) newsgroups (Baym, 1995; 1998) or MUDs (Multi User Dungeon) (Reid, 1999). These are examples of how the computer network technology "*allow for people to create a range of new social spaces in which to meet and interact with one another*" (Kollock & Smith, 1999, pp. 3). Roughly these can be categorised as online communities of special interests in which people participate because they share a common interest. However, the focus in this paper is on a specific kind of online self-help community where people are brought together more by coincidence and by reasons beyond their control. This article identifies and analyses characteristics of **P**atients’ **O**nline **C**ommunities (POC)[1] in Sweden. These online communities might even be categorized as “communities of *unintended* interest” referring to the (sometimes dramatically) changed life situation not controlled by the individual. This means that if the patients did not suffer from the disease they would probably not have taken an interest in it.

Lately patients’ on-line self-help has attracted an increased research interest. Studies in the field have concerned the benefit for patients to participate (Ferguson, 2000) as well as the self-help processes taking place (Finn, 1999) in the groups. Additional studies have focused the quality of the medical information (Ferguson, 2002) while others discuss the transformation of patients as users into producers of medical information (Hardey, 2001) due to their online participation.

Although the increased research interest little attention has been paid to capture the structural and cultural outline of POC. Consequently, the main purpose of the paper is to increase our understanding of how individuals design social online support for difficult life situations.

Additionally, few scholars have focused how an increased knowledge of this unique type of online communities 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 under used (Rice & Katz, 2001) when it comes to the relationship between patients and healthcare. Several studies emphasise the need to use the Internet more effectively in this area (Sittig et al, 2001; Eysenbach & Diepgen, 1999; Ball & Lillis, 2001).

In order to meet the specific needs of patients’ their participation in the development of online health care resources is important (Leimeister et al, 2002). Consequently it is here argued that the design of POC and patients’ use of the Internet for medical information in general (Josefsson, 2002) is a valuable source for design implications. Therefore, an additional purpose of the paper is to introduce a discussion about how the experiences of POC can serve as implications for design of Internet based communication between patients and health care providers.

In order to accomplish this Nancy Baym’s (1995, 1998) model of ‘*the emergence of on-line community*’ is applied. This model takes a constructivist perspective and emphasizes the emergence of an online community as a complex interplay between the participants, the context and the technology. Applying the model for explorative purposes it brings the opportunity to identify both the structures of POC and the cultural dynamics as well as to get an understanding of the complex interplay between these two.

---

[1] Although notions like “self-help groups” or “social support groups” sometimes are used the term Patients’ Online Communities (POC) is preferred in this paper since it more directly make visible the kind of online support group focused.

By applying the model to examine this special kind of online phenomenon designed by individuals the paper contributes to an increased understanding of the functions of online communities and how they support certain practices (Mynatt et al, 1999). More specifically, the paper contributes with a fine-grained picture of the structural and cultural context of a kind of online communities created because of difficult changes in private life situations.

As the use of the Internet in everyday life develops there is a need to learn more about these online activities, their effects and the role of this technology use in peoples lives – offline as well as online (Haythornthwaite & Wellman, 2002). The presented study of POC also contributes as a good example to this growing body of research.

Further, the choice to examine Swedish POC is believed as an important arena for these studies since Sweden and also other Scandinavian countries have a broad access to the Internet at workplaces as well as in private households and public spaces (Sweden Statistics, 2001) although the countries to not have the tradition of self-help as in the Anglo-American countries (Kummervold et al, 2002).

The paper is structured as follows. First, the performed research study is outlined followed by a presentation of Nancy Bayms' model of "The emergence of on-line community". The model is then applied in order to identify and analyse the characteristics of the participating patients online communities. Finally, there is a discussion about distinctive features of POC and their significance for design.

The research study

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

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 use of the Internet for medical information/ pros and cons/ effects on relationship - health care provider and professionals/ ideas of future use of Internet for patients/health care.
Semi-structured interviews	10 interviews with imitators 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 the performed research studies

The first study involved *observations* of Swedish POC on the Internet. The idea was to examine online communities initiated and managed by individuals addressing a special disease or patient group and providing interactive facilities. By the use of Internet search engines like “Altavista”, “Google” and “Yahoo” 15 POC was selected representing diseases such as multiple sclerosis, thyroid problems, fibromyalgia, and whiplash. The time these POC have been online varies between two to seven years. The observations resulted in an initial understanding of the structures of the online phenomenon and the performed practices.

The second study consisted of a minor *questionnaire* in four POC with the purpose to highlight patients’ experiences and expectations of the use of the Internet for medical information and to emphasize their ideas of Internet use in the relationship with healthcare. Two discussion boards and two e-mail lists comprise the four patient online communities 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 Internet use for medical information and what they believe can be improved and further developed.

Even if the original purpose involved an expectation for a larger number of answers, a total of 39 answers were received. The total answer rate can only be estimated approximately since two of the participating communities were open to all visitors of the web pages. The other two communities (the e-mail lists) had a total of 205 members at the time of the questionnaire. Although the questionnaire was limited in several respects the participating patients presented a rich picture of their experiences of various online medical resources. This has served as an important introduction to the area and for future research.

The third study involved ten semi-structured *interviews* with the initiators[2] of ten of the previously observed POC. Seven of the interviewees were women and three were men and the ages varied between 25 and 65. The interviews involved only a few specified question areas involving issues on how and why the communities were initiated and how they have developed since the start. The questions also concerned social and technological issues of online communities as well as future oriented questions. Additionally thoughts on reactions from healthcare on the on-line community activities were treated. Each interview lasted for about 45 to 70 minutes and were tape-recorded and transcribed.

The Emergence of On-Line Community

Drawing on the work by e.g. Contractor & Siebold (1993), Hollingshead & McGrath (1995) and Siebold et al (1994) Nancy Baym (1995, 1998) have

---

[2] Throughout the paper the term “initiator” is used synonymous with the term “owner” both indicating a person who has created and are also managing a POC.

suggested a model originally designed in an attempt to answer the question of "*what occurs online that leads some people to experience them (online communities) as communities in the first place?*"

In the research field of CMC a technology deterministic tradition has been dominating (Baym, 1995). As a contrast the model focus the research work aiming at an understanding of the complex interplay between both human activities and the technology. As thus, the aim of the model is to capture the process in which an online community and its participants create a community culture and a sense of community.

The underlying idea of the 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 pre-existing structures of the community and the participants' appropriation and use of the resources and rules offered by the structures.

In addition, the model offers the identification of important components as well as an understanding of the social activities of online communities. Therefore, as in this article, the model can also be used to analyse special kind of communities in order to increase our knowledge of them as emergent online phenomena.

Supported by the above CMC research work Baym (1995; 1998) start by identifying five pre-existing structures of online communities; *external context, temporal structure, system infrastructure, group purpose* and *participant characteristics*. In the following each of these will be presented[3].

- *External context*: reflects the online environment in which the communication is situated like the technical and social practices along with the group relevant resources brought in to the online community by its participants. This also concerns the location of the immediate access to the technology.
- *Temporal structure*: involve the possibility to communicate synchronous or asynchronous influencing the number of participants as well as the access to immediate feedback and the possibility to write and rewrite messages. Also this concerns the maintenance of archives that bring 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 also 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

---

[3] For a comprehensive reading of the model, see Baym (1995; 1998)

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 pre-existing 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 also the social dynamics of a group need to be considered. According to Baym (1995; 1998) these are the result of the participants' appropriation and use of the resources and rules offered by the pre-existing structures. Drawing on research work on CMC[4] four categories of social dynamics are suggested and discussed. These categories are forms of expression, identity, relationship and behavioural norms. In the following each one of these is briefly addressed.

- Forms of expression: is related 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 off line as well as situations when the opposite occur.
- Behavioural norms: reflect 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 pre-existing structure of the online community. This brings a complex picture of how these online phenomena must be analysed and understood. Hence, in the next section this model is applied to illustrate the structures and cultural context of online communities designed by patients themselves.

---

[4] Baym refers to Reid (1991) on work of Internet Relay Chat (IRC), Myers (1987a; 1987b) for the study of BBSs (Bullentin Board Systems) and Hellerstein (1985) on a study of a university wide network.

Patients' online communities (POC)

Pre-existing structures of POC

External context

The external context of POC involves three important aspects starting with central driving forces behind their existence. The performed questionnaire as well as the interviews shows that for many patients it is important to have the possibility to exchange experiences of their life situation as a patient with others in the same or similar situation. The patients find it important not only to receive social support but also to be able to help others. In the studies they often pointed out that: "I want to help others so they don't have to go through the same thing as I have"[5].

Many patients also want to get more information about their disease than they normally do e.g. at the doctor's office. For some patients this need also become the starting point to create an online community. However, the search for medical information has proven to be a difficult task. The interviewed initiators of POC reported that in their efforts to manage their health situation they found the information about the disease on the Internet inadequate since it is not always available in their own language and not presented in a comprehensive way easily accessible also to the laymen. They showed awareness of the difficulty of incorrect medical information on the Internet and over time they had developed an understanding of how to value different kind of sources. However, this was also an area where they called for "a much more active partaking by health care providing reliable information sources on the Internet", as illustrated by one of the interviewees.

The patients have collected and put together all kind of information about the disease and sometimes they have also translated it and finally they have presented it on a web page. Several of the interviewees expressed this process as a kind of "therapy" for them to cope with the disease and the difficult life situation. One of the interviewees even described the work with the POC as "one of the most important component in my own therapy". The idea to use the Internet was described as means to inform and support others as well as themselves. By the use of the interactive facilities other patients have joined gradually forming a community existing only online.

In addition, for some of the POC initiators in the study their disease is not that well-known and familiar to people in general. Therefore these patients have found

---

[5] Since the research study was performed in Swedish all presented quotes from the observations, the questionnaire and the interviews are translated to English by the author.

the Internet useful also as a space for creating “disease awareness” and to influence the public opinion through the development of a POC.

Both the interviews and the observations show an important second aspect of the external context of POC. That is the accumulated experiences of the disease and interaction with health care providers held by the participating patients. These experiences are communicated e.g. by the personal stories available in the communities, sometimes on special web pages named e.g. “Others’ experiences” or “Fellow patients’ stories”. Here patients tell their story of how they discovered the disease, about meeting the health care provider/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. Here patients draw upon their own and also others’ experiences of the disease to help fellow patients to interpret what doctors and other health care professionals might mean. That is, they try to help each other to understand and make sense of e.g. results from tests or samples and examinations but also what has been discussed at meetings or phone calls with the doctor. In addition, patients also support each other on issues of how to act against health care providers or doctors. In the questionnaire the benefit of these accumulated experiences was often pointed out. Here described by one of the participants:

> “[…] you can discuss with others in the same situation and get an overview of how others deal with similar symptoms or how they experience the contact with the doctor. You get knowledge about your self that helps you to know what to ask for […]”

The third aspect of the external context involves the Internet environment in general, which e.g. includes issues of physical location and Internet access. Participants in POC come from all over Sweden although some communities also have members from other Scandinavian countries as well as Swedes living abroad. A few of the interviewed POC initiators reported that their community have members of other nationalities living in other parts of the world. This means that the patients involved in POC would not likely have meet without the online community. Based on the questionnaire and the interviews the patients mainly access the Internet from their homes as well as their workplaces and seldom from publicly accessible computers in e.g. public libraries.

Temporal structure

In POC patients have the possibility to interact with each other asynchronous as well as synchronous. The observations shows that in some communities there are several facilities available in others just one. The most common feature of asynchronous communication is the discussion board. Here patients can discuss issues of their disease such as different symptoms, when and how a doctor should be contacted and strategies to get the best health care available. Other issues concerns different kind of medicines, their effects and side effects and alternative treatments. In these discussions patients also give each other support and human understanding to handle a difficult and stressful life situation. In most of the communities in the study the discussion boards are open to any visitor but there are also examples when patients must register and become members to log in and participate.

Subjects formulated by the owner of the community often structure the discussions although sometimes the discussions are built in chronological order. This latter way to organize the discussion gives a general view of the frequency of the contributions to the debate. This however, varies between the observed POC in the study and according to the interviews this is also influenced by such occasions as when the disease has attracted mass media attention.

In POC they try to keep archives of former discussions available since these contains much information valuable to patients in several ways. Newcomers and the more experienced participants can use the archives as a recourse since many questions and issues discussed are recurrent. The interviewees emphasised the archives also as an important source of information for patients that, for some reason, do not actively participate in the discussions (“lurkers”).

The same or similar issues as on the discussion boards are also debated on the e-mail lists. Since patients must register and be approved as participants the e-mail lists is a closed community or a closed part of a community. Here non-members or “lurkers” cannot share the information. The owners of the POC in the study are well aware of some patients’ resistance to register and therefore some of the POC provide both an open discussion board and an e-mail list.

An additional kind of interaction is through the “guest book”. The observations showed that the interaction here is characterised by simple messages to the community as such or as feedback of the web pages directed towards the owner. Sometimes contacts for private e-mail exchange are made here.

These different ways to communicate in POC are all examples of asynchronous communication. However, a few of the communities in the study also provide synchronous communication in chats where patients get together and chat on a set time and day of the week.

System infrastructure

Some of the interviewees described how their POC are built mainly by software available for free on the Internet while others have spend private means to get the system infrastructure to work. Also for the physical location of the web pages there are different technical strategies employed in the communities. Some are located at servers for free in exchange for having commercial advertising on the web pages while others choose to pay for a web hotel without the commercials. Others have also bought their own domain name.

In addition, due to the increased access to broadband in Swedish households some of the owners have had the possibility to locate the web pages of the online community to a server at the broadband company for free.

The different strategies for creating the system infrastructure is influenced also by such things as the owners time resources, strength and energy to work with the community as well as their access to and knowledge about the technology and its potentials. For some of the owners the handling of this kind of technology is a part of their professional work while others have learned (e.g. from family members) about the possibilities of the technology while using it. As explained by one of the interviewees:

> “[…] 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.”

Group purposes

The purpose of a POC is often more than just one. The different purposes are linked and change as the community evolves. The group purposes presented here must therefore be considered as representations of the basic purposes common in POC.

The most apparent group purpose in all of the participating online communities is to provide patients with information. The communities want to *inform patients* about the disease in different ways and this is obvious in the online community in several ways, e.g. in text on the “welcome-page” but also by the design of the community pages linking the visitor to pages about ”symptoms”, ”diagnosis”, ”treatments” or ”The disease”. Also “latest news” from the research is often presented. Under these headlines patients can find the information put together and sometimes also translated by the owner of the community. On the web pages it is also common to find a disclaimer that point out that the owner is not a medical professional and that the correctness of the information therefore cannot be guaranteed.

There are also several links to other sources for medical information sometimes both on-line as well as off-line. The basic idea is to help patients to become well informed and to increase their possibilities to handle their situation as a patient and to make informed choices in the healthcare system.

Some POC also provide technical information and service by links to web pages where software necessary to obtain some of the information in the communities can be downloaded. Examples are “Acrobat Reader”, new versions of web browsers or software to open ”Zip-files”.

The purpose to inform is for many of the participating online communities closely related to the purpose to serve as a *learning environment* on the Internet. Several of the interviewed initiators of the online communities reported that when they were diagnosed themselves they wanted to learn more about the disease in many ways. Since they had a hard time to find Internet 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. This purpose is pointed out in the online community by the emphasis of the idea of patients learning about their disease in order to become "their own expert". Also the extensive list of links to other sources of medical information, sometimes referred to as ”recommended readings”, makes the purpose clear.

All the patient online communities in this study have group purposes for creating *social support*. One of the interviewees described this as: "My aim is not only to provide facts but also…even more important…they should get response from someone who understands the hell they often are going through".

The general idea is to support discussions and personal interaction and to serve as a meeting place for fellow patients for social support and human understanding. This purpose becomes visible in the different interactive facilities provided by the online communities. The performed observations of POC shows that patients are encouraged to join the dialogue on the discussion boards or on the e-mail lists. The benefit for patients to participate is clearly pointed out on the web pages as well as in the ongoing discussions. There are also well-described instructions, both technical as well as social, for how to participate.

In most online communities the group purpose of social support is highly emphasized while in a few the purpose to serve as a means to *influence the public opinion* is pointed out as even more important. Since some diseases are not that well-know several of the interviewees pointed at the need to create "disease awareness" among patients and in society at large in order to affect the way these patients are treated in the health care system. These issues are also the topic of much of the information available on the web pages. There are e.g. comments about when the disease has attracted attention in mass media and there are also reprints of articles available originally published in newspapers. There is also information about legal cases concerning the disease. In addition, the purpose becomes clear in the expressed request for patients to participate in a societal discussion, online as well as offline about the terms for the specific patient group.

Participants characteristics

An important characteristic of participants in POC is how long the person has suffered from the disease. Most of the observed POC in the study have a "core group" of participants with long time experience of the disease and of contacts with health care. Participants of the questionnaire describe how these members frequently share their experience and enjoy providing the help and support they earlier missed themselves during their period of illness. On the other hand there are newcomers representing other characteristics with their specific questions and need for extra support and understanding related to their stressful situation as newly diagnosed.

Besides the experience of the disease the participants also varies to the extent of technical experiences. Some are familiar with the technology because of their work practices while others have started to use computer technology as they became ill. Regardless of experience the patients wanted to have the opportunity to search for additional information on the Internet and this was often expressed like “the natural thing to do these days when facing illness”.

In addition, the performed studies shows that the disease in question also decides some of the participant characteristics. For instance, when a disease strikes only one sex the online community will consist of only men or women. In addition, there are also POC with participants in basically the same age since the disease might concern people in a certain age or affect them most in a certain period of their lives, like diseases related to infertility problems.

Social dynamics of POC

The pre-existing structures represent the basics of POC. However, alone these are not enough to give a comprehensive view of the communities. In order to deepen the picture the social dynamics of POC should be added. In the following this is accomplished by the examination of the *forms of expression* used together with *identities, relationships* and *behavioural norms* in the POC. In addition, influences of the pre-existing structures are also exemplified.

Forms of expression

A central characteristic of POC is to share each other’s stories of the disease. This means that the participants provide very personal and sometimes delicate information about the experiences of the disease and the changed life situation. The forms of expression can be categorized as personal and intimate. This is clear both on the special web pages providing these stories and in the discussion boards. However, in the study the interviewed patients reported that the dialogue on the e-mail lists often gets even closer since it is considered a private group.

The performed observations as well as the interviews showed that the use of a medical language and terminology also distinguish the forms of expression in the POC. This involves terms for different medical tests and examinations but also other characteristics of the specific disease.

An additional characteristic of the way patients express themselves in POC is the use of humour. Jokes about the disease or funny stories about how patients have been treated by health care are common. The stories report of comments or medical advises from doctors or other health care professionals that patients have considered completely wrong and ridiculous. These stories become group specific jokes and in some POC they have their own special web page. “Sometimes, you just have to be able to laugh at all the misery” as expressed by one of the interview participants.

In various ways the forms of expression highlighted here are influenced by the pre-existing structures of POC. The life situation of suffering from a chronic disease (external context) and the need for social support contributes to the shaping of the vocabulary used in communities and the personal way of expression. Also the different interactive facilitates (temporal structure) and how they are used (system infrastructure) affects the forms of expression. For instance, in the chats available in some of the POC the conversations among the participants are synchronic and making the dialogue more direct and personal.

Both newcomers and patients with a long time experience (patients characteristics) of the disease contribute to the forms of expression in POC. For instance, newcomers often express issues of anxiety and fear of their health situation and this affect the use of a personal way of expression. On the other hand, patients with long time experience are aware of what someone just diagnosed are going through and this also affect their contribution to the dialogue about the disease. Also the group purpose influences the forms of expression. An example of this is the different expectations and different strategies for how to express one self when the purpose of the group is to provide social support and human understanding among fellow patients as opposed to POC were the purpose is to influence the public opinion.

Identities

In POC patients can participate anonymously or by using their real names. However, in some communities participants have to prove themselves as trustworthy if they use both a nickname and an e-mail address not indicating their identity. This means that the creation of identity is often based on the perceived quality of the contribution as well as the frequency of participation. To create an identity as well known or “famous” in the group participants also have to prove their experience and competence. If they succeed they get others’ trust and are considered as reliable in discussions. Some of the interviewees emphasised that this identity also becomes an important resource in the POC as someone who can give support to many and answer various questions about the disease.

In addition, the way identities are created in POC is related to the personal style of the community owner. His or her strategies for how to run the community play a central role. An example is decisions about such things as whether the community should be open to any visitor or if a membership should be required. If a membership is needed to join it is also the owner who decides the criteria for who should be allowed to become a member. The strategy applied by one of the owner was described like:

> “[…] they should also have been writing during a period of time and showed that they are active on the list. Activity involves both asking and answering. Not just to give answers and no only to ask. You have to share, you know […]”.

By the work to initiate and run the POC the identity of the owner is created. However, this identity has for many changed as the communities have evolved over time. The development has often put them in a leading and central position not only for the online community as such but also as an important support person for patients needing help. For some owners this has become so stressful that they have chosen a strategy to reduce the focus on themselves in the POC and direct as much attention as possible towards issues of the disease. Still, in most of the POC in the study the owners play a central role as coordinator of information as well as moderator of the discussions. They also have the main responsibility for the development of the community.

The experience of the disease (external context) and the situation as patient (participant characteristics) together with the exchange of rather personal information makes the creation of identities oriented towards anonymity but with gradual disclosure either of true identity or accepted identity as a “famous” group expert. Also a group purpose directed towards support and human understanding of fellow patients will influence the creation of identities in a similar way.

In addition, the temporal structure and system infrastructure for participation in discussions is also reflected in the creation of identities. Following an ongoing discussion or reading a past one in the archives shows e.g. who has been active in discussions, who is considered reliable etc. This brings a picture of the participants in the community that affect the creation and maintenance of identities.

Relationship

POC only exist online but in several of the participating communities the activities online has resulted in get-togethers off-line as well. Several of the interviewed patients reported that when patients have participated for a while and gradually revealed more of themselves some of them have discovered that they live in the same town or in the same part of the country. The patients then arrange informal meetings at e.g. a café. The purpose is just to talk directly to each other and to see what their online friends look like in real life.

In some of the POC in the study also the opposite situation exists where patients who know each other off-line also have developed an online relationship.

An additional example of how relationships are formed in POC is when “off-topic lists” are created. This happens when patients who get to know each other in the community want to develop their online relationship and to be able to discuss other topics than those related to the disease.

One of the underlying ideas of POC is to meet fellow patients and as thus the pre-existing structures affect the creation of relationships. When the group purpose is to support each other despite geographical distances (external context) the creation of relationships is something the participants strive for. However, that is not to say that all patients have a need for the same kind of relationship. The need of newcomers might be different from those who have long time experience of participating in a POC (participant characteristic). The design of the system infrastructure with diverse set of interactive facilities that allows for different levels of privacy together with various temporal structures influence the forming of relationships in POC.

Behavioural norms

The observations of the POC illustrate that there are often both technical and social guidelines for how to participate in the discussions. The technical part involve such instructions as for how to quote others when answering e-mails and how to correctly make contributions on a discussion board.

The rules for “netiquette” often serve as guidelines to inform the participants what is socially accepted or not in the discussions. In the POC it is also pointed out that since the participants are patients sometimes in the most difficult life situation and that some issues discussed concern delicate patient information it is even more important to keep the dialogue in good manners. Unfortunately these guidelines is not respected by all participants and most of the interviewed initiators of POC have experiences of ‘flamers’ who insult others, ruin the dialogue and bring the discussions to concern issues far beyond the original ones. When these things occur the owner normally excludes the flamer from the community.

There are also other occasions when participants are excluded. Sometimes people who are not suffering from the disease pretend to be patients and join the group. These people might not be flamers and their reasons for joining the communities is not always known. The interviewees reported that some of these persons want to use e.g. the discussion board for political discussions while others just want to talk to someone. Therefore, in some of the POC the use of a trial period is employed. For instance, a patient who wants to become a member of an e-mail list will have to prove him/her self in the community by actively participating in the discussions and prove their knowledge of the disease and the situation as a patient enough to actually be a patient.

Also the shaping of behavioural norms is influenced by the pre-existing structures. The driving forces (external context) involved in the need to meet other patients also brings the necessity to form the manner for how these meetings technically and socially can be structured. In addition, if the purpose of the community is mainly oriented towards support and human understanding norms for social behaviour becomes vital. Since POC continuously get new participants with different experiences of Internet use and participation in online communities (participants characteristics) the way the discussions are performed and the accepted social behaviour needs to be communicated.

The system infrastructure available with various possibilities for dialogues using both asynchronous and synchronous (temporal structure) interaction influences the creation of behavioural norms. Representing different technical facilities discussion boards, e-mail lists or chats involve different technical behaviour like for how to join and how to participate.

Discussion

The results bring a fine-grained picture of POC as an emergent online phenomenon. By applying Baym's model contextual structures as well as the community culture becomes visible. The model brings out more than a specification of the entities that constitute this kind of online communities since it also reveals the social dynamics of the discourse and the way relationships, identities and norms are developed.

Further, the use of the model contributes to the highlighting of two important underlying needs of patients essential for the existence of the online communities. Therefore, in the following discussion these needs as central aspects of the external context of POC and their contribution to the specific social and the technical design will be focused. In addition, the discussion will also show how the results can inform design of emergent forms of Internet use between patients and health care providers.

To be diagnosed with a chronic disease is a very stressful and difficult situation that often involves a changed life situation for the individual as well as for his or her family. This generates needs to create meaning of the disease and to understand the new situation (Madara, 1997). For many patients increased knowledge of the disease and discussions with fellow patients becomes a strategy to deal with the uncertainty of the situation.

This means that patients develop needs *to get informed* and *to interact with others* in the same situation (Madara, ibid.). These needs become the fundamental driving forces of POC and also important components of the *external context* making POC unique as online communities.

The driving forces are shaped by a life situation beyond control of the individual and that make POC different from other "communities of interest". People do not start or join these online communities because they have taken a mere interest in a disease but because their life situation has changed due to causes they cannot control themselves.

The driving forces highly influence the design of POC. The needs to interact and to get informed trigger the initiation of POC and shapes the *group purposes*. Although the purposes may vary they all have their basics in the requirements for additional information and communication with fellow patients. This also triggers different categories of patients to participate, which influence the *participant characteristics*. Further, the driving forces also influence the means by which patients try to fulfil the needs. This results in the search for and use of various interactive facilities creating the *system infrastructure* and it also influence how patients design their interactions in terms of *temporal structure*. Additionally, the driving forces highly influence the development of the *social dynamics* of POC. The underlying need to learn more about the disease and to share a difficult life situation with others sets the frame of the discourse and also shapes the community culture in which the social behaviour is decided and developed.

This specific design and the interrelated dependencies between the pre-existing structures and the social dynamics of POC provide several important areas to analyse from a design perspective. However, with the purpose to introduce a discussion of how the experiences of POC can inform design the following will focus the main driving forces of these online communities as implications for design of emergent *Internet based communication between patients and health care providers*. The information technology use referred to is the kind emphasised by Rice (2001) that involve both health care providers and patients in the development future health communication. Providing a concrete example Leimeister et al (2002) discuss this kind of utilization of the technology in their efforts of designing mobile health communities for cancer patients involving both health care providers/professionals and patients.

First, the design must allow for patients to become well informed. That is, providing patients with medical information of high quality presented in their own language and in a way accessible also to the laymen. The issues of providing patients with reliable medical information online and how this successfully can be implemented are ongoing discussions (c.f. Ferguson, 2000; 2002; Eysenbach & Diepgen, 1999). However, in this study it is highlighted by patients’ requirements for health care to increase their activities in providing online resources that guarantee the correctness of the medical information.

Further, the patients have high demands on the news value of the information. This means that the information must be updated regularly and complemented with news from ongoing research in the specific field.

Also, the information provided must not only give general information about the disease like causes, symptoms, treatments and prognosis but also specific information (Leimeister et al, 2002). This involve issues related to the individual case of illness like explanation of particular test results, how medications can be used and combined or further examinations and treatments that a patients should discuss with his/her treating physician. It also involves opportunities to discuss additional medical information available on the Internet with health care professionals.

Second, the design should offer patients the opportunity to get contact with fellow sufferers. The benefits for patients sharing their experiences are well known (Reeves, 2000) and how this supports the self-help processes (Finn, 1999; Preece, 1999) involved. This concerns the possibility to personally receive social support as well as helping others (Madara, 1997; Reeves, 2000). This is also important since the Internet never rests and that patients can use this resource to contact others at any time. Such facilities for online meetings between patients are especially valuable for patients with physical or mental difficulties to participate in off-line activities (Finn, 1999).

Additionally, it is important to keep in mind that patients have different strategies for how to utilize the Internet for self-help purposes and this concerns also different views on anonymity and the participation in online activities. Many patients show awareness of the importance and personal benefits involved in the possibility to follow patients' discussions without actively participate. This brings the idea that the design should support these patients, that for some reason do not participate, to learn from others and have their own story confirmed. On the other hand, there are also patients feeling uncomfortable with arrangements allowing for "lurkers" to follow ongoing discussions. Therefore, the design must *also* provide more closed spaces for online debate requiring registration or membership, making "lurking" more difficult.

Arrangements as outlined above would be beneficial also for health care providers or professionals. The kind of information provided in patients' interaction with each other is difficult for health care to communicate to patients. Therefore, an online health care resource, wholly or partly, devoted to social support can be a valuable resource for health care to guide future patients to.

The suggested design implications demand an active participation of health care providers to establish an Internet based communication and by means of the technology support patients in a new way in their efforts to make sense of a disease and a changed life situation. This implies a way to use the Internet for a continuing interaction creating on-line communities involving both healthcare providers and patients (Josefsson, 2002). According to Mittman & 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*" (pp. 48).

In order to develop Internet use towards a health care resource as proposed future work should consider both technical and social issues (Preece, 2000) in order to increase the knowledge of how to make the Internet serve the interests of patients as well as healthcare. This paper contributes by drawing attention to a unique kind online communities designed by patients themselves and the driving forces underlying the development of POC. The reported study only considers a limited number of Swedish patient online communities chosen from specified criteria. However, the presented picture provides an important example of the emergent use of the Internet in everyday life designed by individuals and how studies of these online phenomena can inform design.

Conclusions

In this paper the characteristics of patients' online communities in Sweden has been identified and analysed using Baym's model of "*The Emergence of On-Line Community*". The purpose has been to increase our understanding of how individuals design online social support and how this can inform design in a wider perspective. By applying the model the paper presents a fine-grained picture of POC covering both the contextual structures as well as the community culture. Further, the model contributes to the highlighting of two important driving forces of POC (*to get informed* and *to interact with others* in similar situation). These serve as a basis for the introductory discussion provided on how the experiences can serve as implications for the emergent design of Internet based communication between patients and health care providers.

References

Ball, M.J. & Lillis, J. (2001) E-health: transforming the physician/patient relationship, *International Journal of Medical Informatics*, 61, 1-10.

Baym, N. (1995) The emergence of community in computer mediated communication. In S.G. Jones (Ed.), *CyberSociety: Computer-mediated community and communication*, pp. 138-163. Thousand Oaks; CA: Sage Publications.

Baym, N. (1998) The Emergence of On-Line Community. In S.G. Jones (Ed.), *CyberSociety 2.0: Revisiting Computer-Mediated Communication and Community*, pp. 35-68. Thousand Oaks; CA: Sage Publications.

Contractor, N., S. & Seibold, D., R. (1993) Theoretical Frameworks for the Study of Structuring Processes in Group Decision Support Systems. *Human Communication Research*, Vol 19, No 4, pp. 528-563.

Eysenbach, G. & Diepgen, T. (1999) Patients Looking for Information on the Internet and Seeking Teleadvice, *Journal of American Medical Association* 135, 151-156.

Ferguson, T. (2000) On-line patient-helpers and physicians working together: a new partnership for high quality health care, *British Medical Journal* 321: 1129-1132.

Ferguson, T. (2002) From patients to end users, *British Medical Journal* 324: 555-556.

Finn, J. (1999) An exploration of helping processes in an online self-help group focusing on issues of disability, *Health & Social Work* 24(3), 220-231.

Hardey, M. (2001) ‘E-health’: The Internet and the transformation of patients into consumers and producers of health knowledge. *Information, Communication & Society*. Vol 4, No 3, pp. 388-405.

Haythornthwaite, C. & Wellman, B. (2002) The Internet in Everyday Life. An introduction. In B. Wellman & C. Haythornthwaite (Eds.) *The Internet in Everyday Life*. Malden, MA, USA: Blackwell Publishers Ltd.

Hellerstein, L. N. (1985) The social use of electronic communication at a major university. *Computers and the Social Sciences*, Vol 1, pp.191-197.

Hollingshead, A., B. & McGrath, J., E. (1995) Computer-assisted groups: a critical review of the empirical research. In R.A. Guzzo & E. Salas (Eds.) *Team effectiveness and decision making in organization*, pp. 46-78. Jossey-Bass Publishers, San Francisco.

Josefsson, U. (2002) Internet as a Healthcare resource. Patients’ requirements for community building. *In Proceedings of Information Systems Research in Scandinavia, IRIS 25,* August 10-13, Bautahöj, Denmark.

Kahn, C.E. (2000) Design and implementation of an Internet-based health information resource, *Computfer Methods and Programs in Biomedicine* 63, 85-97.

Kollock, P. & Smith, M.A. (1999) Communities in Cyberspace, in M.A, Smith, & P. Kollock (Eds.) *Communities in Cyberspace*, pp. 3-25. Routledge, London.

Kummervold, P., E., Gammon, D., Bergvik, S., Johnsen, J-A., K., Hasvold, T., Rosenvinge, J. H. (2002) Social support in a wired world: use of online mental health forums in Norway. *Nord J Psychiatry* Vol. 56:59-65.

Leimeister, J.M. Daum, M., Krcmar, H (2002) Mobile Virtual Healthcare Communities: An Approach to Community Engineering For Cancer Patients. In *Proceedings of the Xth European Conference on Information Systems, ECIS*, Wrycza, S. (Ed), pp. 1626-1637. GDansk/Danzig, Poland.

Madara, E. J. (1997) The mutual-aid self-help online revolution, *Social Policy*, Spring97, Vol. 27(3), pp. 20-27.

Mittman, R. & Cain, M. (2001), The Future of the Internet in Health Care: A Five-Year Forecast in Rice, R.E. & Katz, J.E (eds) *The Internet and Health Communication. Experiences and Expectation,* Sage Publications, Thousand Oaks, pp 47-73.

Myers, D. (1987a) A new environment for communication play: On-line play. In G.A. Fine (Ed.), *Meaningful play, playful meaning* (pp. 231-245). Champaign, IL: Human Kinetics.

Myers, D. (1987b) “Anonymity is part of the magic”: Individual manipulation of computer-mediated communication contexts. *Qualitative Sociology,* Vol. 19, No. 3, pp. 251-266.

Mynatt, E., D., Adler, A., Ito, M., Linde, C., O’Day, V., L. (1999) The Network Communities of SeniorNet. In S. Bödker, M. Kyng and K. Schmidt (Eds.). *Proceedings of the Sixth European Conference on Computer-Supported Cooperative Work*, 12-16 September, Copenhagen, Denmark.

Preece, J. (1999) Empathic communities: Balancing emotional and factual communication. Interacting with Computers, *The Interdisciplinary Journal of Human-Computer Interaction*. 12, 1, 63-77.

Preece, J. (2000), *Online Communities. Designing Usability, Supporting Sociability*, John Wiley & sons, LTD, New York, USA.

Reeves, P. M. (2000) Coping in Cyberspace: The Impact of Internet Use on the Ability of HIV-Positive Individuals to Deal with Their Illness, *Journal of Health communication*, Vol. 5 (Supplement), pp. 47-59.

Reid, E. (1991) *Electropolis: Communication and community on Internet Relay Chat.* Unpublished Master's thesis, University of Melbourne, Australia.

Reid, E. (1999) Hierarchy and power. Social control in cyberspace. In M. A. Smith & P. Kollock (Eds.), *Communities in Cyberspace*. London: Routledge.

Rice, R.E. (2001) The Internet and Health Communication: A Framework of Experiences, in R.E. Rice & J.E. Katz (eds.) *The Internet and Health Communication. Experiences and Expectation*, Sage Publications, Thousand Oaks.

Rice, R.E. & Katz, J.E. (2001) *The Internet and Health Communication. Experiences and Expectation*, Sage Publications, Thousand Oaks.

Siebold, D.R., Heller, M.A. & Contractor, N.S. (1994) Group decision support systems (GDSS): Review, taxonomy, and research agenda. In B. Kovacic (Ed.) *New Approaches to Organizational Communication*, pp. 143-168, Albany, State University of New York Press.

Sittig, D.F., King, S. & Hazelhurst, B.L. (2001), A survey of patient-provider e-mail communication: what do patients think? *International Journal of Medical Informatics* 61(1), 71-80.

Sveningsson, M. (2001) *Creating a Sense of Community*. Dissertation. Linköping Studies in Arts and Science. No. 233.

Sweden Statistics (2001) *IT at home and in the enterprise - a statistical description of Sweden*, Report from Statistics Sweden, 2001-01-31.