Association for Information Systems
AIS Electronic Library (AISeL)

2006

An Empirical Analysis of the Demand for E-Services for Virtual Communities of Patients

Achim Dannecker

Universität der Bundeswehr München, Achim.Dannecker@unibw.de

Ulrike Lechner

Universität der Bundeswehr München, Ulrike.Lechner@unibw.de

Follow this and additional works at: http://aisel.aisnet.org/bled2006

An Empirical Analysis of the Demand for E-Services for Virtual Communities of Patients

Achim Dannecker, Ulrike Lechner

Universität der Bundeswehr München, Germany
Achim.Dannecker@unibw.de , Ulrike.Lechner@unibw.de

Abstract

Virtual communities of patients provide health-related information and mutual support for members. This paper presents a structured analysis of virtual communities of patients and the demand for novel electronic services. Results include success factors of virtual communities of patients, the structural relations between success factors, demand for new and long-term members and newly and long-term affected patients.

Keywords: *Virtual Community, e-health, e-services*

1. Introduction and Motivation

Virtual communities of patients (also mentioned as virtual communities in health care – VCHC) provide today mainly information and mutual support for their members. Today they provide information concerning diseases, treatments or new research results. Information shared among members includes experience reports on how the disease was contracted, how it affects the daily life and how to cope with it or even how to overcome it. In some VCHC, experiences with medical institutions, medics or treatments are being discussed.

The amount of health related information online and the number and variety of health-related online services increases rapidly. The value add of VCHC however changed only little since VCHC were described in e-business literature. Thus, it seems about time to look into novel e-services to strengthen and enhance VCHC.

Our research on success factors and e-services for VCHC is motivated twofold. First, we think that strong VCHC benefit patients, as patients look for reliable information, need mutual support and orientation. Second, we expect that novel e-services are able to strengthen VCHC by attracting more members, by motivating them to contribute more and more regular and by collecting more and different kinds of information. This is also reflected by our results, e.g., the part of quality management by collecting experience reports and ratings and the support of medical research by the community.

The paper is organized as follows. First, we present in Sect. 2 the state of the art and literature review on self-help organizations and groups, online communities of patients and virtual communities. The research approach is introduced in Sect. 3. Results concerning the demographic characteristics of our empirical study follow in Sect. 4. Sect. 5 presents success factors important to operators and members of VCHC that led to the research model presented in Sect 6. Target group specific needs and e-services presented in Sect. 7. A discussion about e-services for VCHC that fit the needs of their members in Sect. 8 concludes this paper.

2. Health Care and Virtual Health Communities

The health care is in a constant process of reorganization and offers new opportunities to new marketplaces and e-services (Kartseva and Tan 2005). People use the Internet to find health related information, manage their personal health record via the Internet, get information about health care services and regulations that govern them (Goldschmidt 2005; Hulstijn and Tan 2005; Pratt, Unruh et al. 2006). The integration of the information available via the Internet with information people received by physicians is an important factor to make complex decisions (Pratt, Unruh et al. 2006). Let us analyze the current situation in self-help of patients first and to what extent virtual communities can contribute to empower self-help groups.

2.1 Self-Help Organizations and Groups of Patients

Self-help organizations and self-help groups are the "traditional", off-line form for people that are affected by a disease to exchange experiences.

Self-help organizations typically inform members about all aspects of a disease and they act as representative (patient unions). Janke et al. postulate that patients in self-help organizations are better informed on their disease than patients not attached to self-help organizations (Janke, Klump et al. 2005). Borgaonkar et al. show that that providing disease-related information only to patients worsens health-related quality of life (HRQOL) in inflammatory bowel disease (Borgaonkar, Townson et al. 2002). Interviews with operators of self help organizations confirmed that providing information only and constantly reminding on the patient's illness (e.g. through mailing, brochures or newsletters) is counterproductive and frequently leads to the cancellation of the self-help organization membership. Kennedy et al. (Kennedy, Robinson et al. 2003) showed "…patients given a patient-developed guidebook of self-management skills experienced significantly improved HRQOL". This again reminds that e-services that provide information only are not sufficient.

The participants in self-help groups meet each other on a regular basis mainly to exchange information related to a disease. Self-help groups have two main goals: mutual support and exchange of information (Borgetto 2004). Participants benefit from experiencing that they are not the only one affected by a disease or the only ones with particular symptoms and disease related problems in the daily life. Topics discussed in self-help groups include medics, clinical institutions, rehabilitation centers, treatments, medicaments, research and participation in clinical studies.

2.2 Online Health Communities and Health-Related Information Consumer

Today, many of the self-help organizations have online communities or at least some forums somewhere at their website. An interview partner in our study (community manager in an online community) described the typical situation and that little has

changed in the past years – as the forum has the size of approximately 100 regular, but mostly not long time visitors. The same "newbie" questions are being asked over and over again, with the same (possibly dangerous) theories about origin of the disease and possible cures being discussed in a not very profound way over and over again, with newly diagnosed people coming to the forum asking one or two urgent questions and leaving again. Only relatively few people stay for a longer time and the profound discussions take place only partly online in the forum. This self-help organization is however proud of the collection of relevant medical information it provides and of the many members it has and that it reaches over a newsletter.

A look at the online groups of patients not associated with a self-help organization shows that there are plenty of them, a lot of them with hardly any online traffic, many of them are dedicated to a particular disease together with particular theory of origin and treatment with little (open-minded) discussion going on (Dannecker and Lechner 2004; Yahoo 2005). Important to virtual communities is the kindness and appreciation the people give each other, this is a challenge for operators to handle (Preece 2004). That people do not contribute (lurkers) is no problem because of the similar reason the people are part of the VCHC and they are motivated to share their knowledge (Nonnecke and Preece 2001; Nonnecke, Preece et al. 2004; McLure Wasko and Faraj 2005). The type of contributions members of VCHC are able to do are the main aspects that have to be considered if developing new e-services for VCHC (Dannecker and Lechner 2005; Dannecker and Lechner 2006).

The number of groups listed in respective categories at Yahoo alone has nearly doubled from 40.000 in August 2004 up to 74.000 in May 2005 (Dannecker and Lechner 2004; Yahoo 2005).

We conclude that neither the online communities that are dedicated to an illness related topic nor the communities that are associated with self-help organizations are performing very well. Let us have a look at the state of the art in the field of virtual communities.

2.3   Virtual Communities

Particular to VCHC is the integration of offline world (the disease and how it affects the life) and the online world of information and mutual support. "The Integration Principle" details six relations between "real" (offline) world together with the online world (Suler 2000): (1) Telling online companions about one's offline life. (2) Telling offline companions about one's online life. (3) Meeting online companions in-person (4) Meeting offline companions online (5) Bringing online behavior offline (6) Bringing offline behavior online. Suller postulates, that "translating troublesome issues from one realm to the other can be helpful, even therapeutic…".

Let us look at what defines the online world of virtual communities. The contributions of members distinguish virtual communities from other organizations or business models in the digital economy (Timmers 1998). Members contribute information and develop an atmosphere of trust which is prerequisite for collaboration or complex transactions (McKnight, Choudhury et al. 2002). Knowledge contribution and sharing is a complex and social process that involves different actors that have different needs and goals (McLure Wasko and Faraj 2005).

Rheingold describes how this social network emerges. He defines a virtual community as a "social aggregation" that emerges in cyberspace " when enough people carry on discussions long enough, with human feeling, to form "webs" of personal relationships" (Rheingold 1994). Virtual communities are characterized by rules of interaction, value system, mutual trust, common goals and interests (Whittaker and O`Day 1997; Figallo 1998; Schubert 1999; Preece 2000; Wellmann 2001).

Let us have a look at particular properties and the use of e-services. Based on Hamman, a virtual community can be characterized by: (1) a group of actors, (2) (social) interaction, (3) bonding between the actors and other members of the community and (4) the common place (Hamman 2003). Leimeister et al. have developed a ranking of technological, organizational and social success factors for virtual communities in general (Leimeister, Sidiras et al. 2004).

Particular to the field of virtual communities is the degree of differentiation. While contributions by members and social relations are keys for almost all communities, communities differentiate themselves in interaction, the use of e-services according to their joint interest (Hummel and Lechner 2001). Moreover, the nature of the disease leads to differentiation in e-service usage for VCHC (Dannecker and Lechner 2004).

We hope that our research benefits people with chronic diseases by establishing novel e-services. However, since self-help groups, organizations and VCHC are very special in terms of information that is exchanged, the social relations between members or participants and the integration of online and offline world this has to be done very carefully. Objective of this research is to obtain insight into the need for e-services based on empirical data.

3.   Research Method

The objective of our research is to develop e-services for virtual communities. As VCHC are expected to be different from VCs in general, we did a survey to find our about success factors and demand for e-services.

A questionnaire was developed on the basis of a study of web communities (Dannecker and Lechner 2004), interview with self-help groups leaders, an empirical study of Leimeister (Leimeister, Sidiras et al. 2004), and a literature review. Two versions of the questionnaire were created: one for the members and one for the operators of the VCHC. Operators provide community platform and typically the contact data of operators are provided at the website of a community. Ten VCHC (we already had relations to these sites) were contacted to send their operators a first version of the questionnaire with the request to review the questionnaire.

We found VCHC in the German speaking context based on an Internet research done on Yahoo and Google. Cross linked sites in the context of VCHC were also taken into consideration. 250 VCHC in the German speaking context were identified. VCHC with less than 50 members and communities with the most recent contribution older than one year were eliminated. This led to 117 VCHC from which 73 (63%) were chosen randomly and the ten VCHC to which the first version of the questionnaire was sent were added to the sample.

The questionnaire was sent to the operators of VCHC with the request to support the study and to provide a link to the questionnaire to their members and to fill out the operator version of the questionnaire. The questionnaire was available in the Internet for three weeks in June 2005. After eliminating all empty entries and duplicate entries (same values and session id), 295 entries of members and 21 entries of operators formed the sample.

For interpretation and validation of quantitative results, qualitative interviews with operators and members as well as two presentations with the management team of two self-help organizations have been done.

Following the empirical study of Leimeister et al. (Leimeister, Sidiras et al. 2004) a bipolar verbal ordinal scale (see Table 1) was used for most questions such that statements were to be accepted or rejected.

Table 1: *Bipolar ordinal scale and re-interpretation into numbers.*

Agree strongly	Agree	Undecided	Reject	Reject strongly		Not specified
=1	=2	=3	=4	=5		=9

4.   Demographic Characteristics

People participating in this study are active in a total of 145 different VCHC. The „Top Ten" of the VCHC according to the number study participants account for about 50% of the participants:

Table 2: *Top-Ten of the VCHC according to the number study participants*

	VCHC	**Number of participants**	**Ratio**
1	rheuma-online.de (rheumatism)	50	11,74%
2	fibromyalgie-aktuell.de (pain patients)	35	8,22%
3	dccv.de (morbus crohn / colitis ulcerosa)	31	7,28%
4	croehnchen-klub.de (morbus crohn / colitis ulcerosa)	24	5,59%
5	sylvia.at (morbus crohn / colitis ulcerosa)	15	3,50%
6	diabetes-world.net (diabetes)	14	3,26%
7	prostatakrebse.de (prostate cancer)	14	3,26%
8	sd-krebs.de (thyroid cancer)	10	2,33%
9	leukaemie-betroffene.de (leukemia)	9	2,10%
10	prostatakrebse.de (prostate cancer)	9	2,10%

16 communities account for two study participants and 100 communities for one participant. More than 95% of the study participants are affected by a chronic illness. Most participants suffer from rheumatism (incl. fibromyalgie) (20%), followed by morbus crohn (17%), cancer (11%), diabetes (6%) and tinnitus (5%). Note that the majority of participants are affected by a chronic disease which allows an analysis on an homogenous sample.

The research sample ($N_{members}$ = 295, $N_{operators}$ = 21) consists of 69% female and 31% male participants. Below selected information about participating members and operators of virtual communities is being provided. Table 3 lists a sample of the demographic characteristics:

Table 3: *Demographic characteristics of participants*

	Members	**Operators**
Gender f / m	208 / 87	10 / 11
Average age	41,68	40,52
Number of memberships in VCHC	1,50	1,38
Member since (years)?	2,22	4,55
Are you affected by the disease?	yes 281 / no 14	yes 11 / no 10
How long are you affected by the disease?	9,89	6,95
Do you join meetings of self-help groups (SHG)? (very often 1 – never 5)	yes 154 / no 141 4,01	yes 16 / no 5 3,86
Where do you feel more comfortable? VCHC / the same / SHG	115 / 159 / 21	9 / 11 / 1
How often do you write articles within the forum? (several times a day 1 – weekly 3 – never 5)	3,12	2,19

Particular for an online study are an average age of above 40 years and a very high percentage of women in the categories members and operators. The participants contribute more than once a week in average. In average the members are affected by their illness for nearly 10 years, and their time of membership in average is two years and four months which is rather long.

5. Success Factors

The first step is an analysis of the success factors (i.e. what is relevant to those members) of virtual communities in health care. We distinguish members and operators. The 17 most important success factors are ordered by the member perspective in Figure 1. The figure presents an abbreviated version of the original question together with the arithmetic mean of the answers. The sample was tested due to normal distribution using an exact "Kolmogorov-Smirnov-Test" and all results are significant with p<.001.
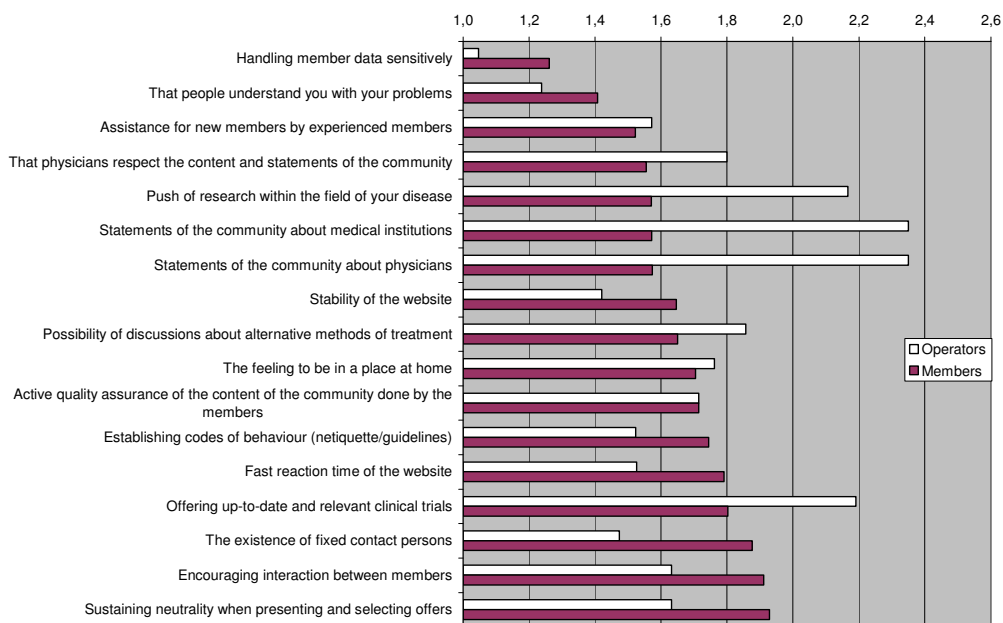
*Figure 1: Top 17 success factors ordered by the member views
(highly agree 1 – highly disagree 5)*

As expected handling member data is the most important factor for the members and it is considered even more important by the operators. The feeling of being understood with problems within the VCHC is next, followed by the assistance of new members by experienced members.

Note that the list of top success factors contains technical issues like the stability of the web site, social issues like the feeling of being understood or feeling at home in the VCHC are included in the top 17 success factors. Note furthermore that six success factors concerning medical issues are important and of special interest. These factors are that physicians respect the content and statements of the community, support of medical research, statements about medical institutions and physicians, possibility to discuss alternative methods of treatments and offering up-to-date and relevant clinical studies.

Note the difference in operator and member view in several success factors. The difference between operator and member occurs in aspects concerning the medical information a community contributes (that physicians respect the content available in communities, statements of the community about medical institutions and physicians and offering up-to-date information about medical trials). This is reflected by the current situation as VCHC hardly provide e-services for members to contribute experiences with physicians, treatments… in a structured way. This difference was explained in interviews with operators that were concerned whether such kinds of contributions would be feasible or members would appreciate such kind of e-service. So operators would not try to provide such e-services and since VCHC typically are sort of underfinanced, customized development or trials for the VCHC are hardly possible.

The next step is to research on the interdependencies of success factors and determine (clusters of) success factors that can be influenced by novel e-services to strengthen VCHC.

6.   Research Model

To achieve a more structured approach to the analysis of the needs for novel e-services we have developed a research model to figure out the main parts concerning a future VCHC and the interdependencies of these main parts due to the bonding of the VCHC.

Reflecting the literature (cf Sect. 2) and the results of the factor analysis (see Appendix A) seven components are defined in Tab. 4:

Table 4: *Components of the research model (for the questions cf. Appendix A)*

Component	Description
Perceived Operator Role (O)	Describes the role of the operator from a member perspective.
Perceived Bonding (B)	Describes how important the bonding between members and the VCHC and the social context between the members is.
Perceived Ease of Use (EoU)	Describes how easy the use of the information technology is from a member perspective.
Perceived Medical Aspects (M)	Describes medical content and the medical research areas the members of the VCHC are interested in.
Perceived Quality Assurance driven by the operator (QAO)	Describes the quality assurance actions done by the operator.
Perceived Interaction (I)	Describes the types of interaction within the VCHC.
Perceived Quality Assurance driven by the community (QAC)	Describes the quality assurance actions done by the members.

The components (see Table 4) followed, a structural equation model was estimated by AMOS 5 (Byrne 2001) using a maximum likelihood estimation. The values of the model are within an acceptable range (RMSEA = .033). All standardized regression coefficients are significant at $p < .001$ (beside QAO->B $p = .009$ and O->B $p = .002$). In Figure 2 only the latent variables.
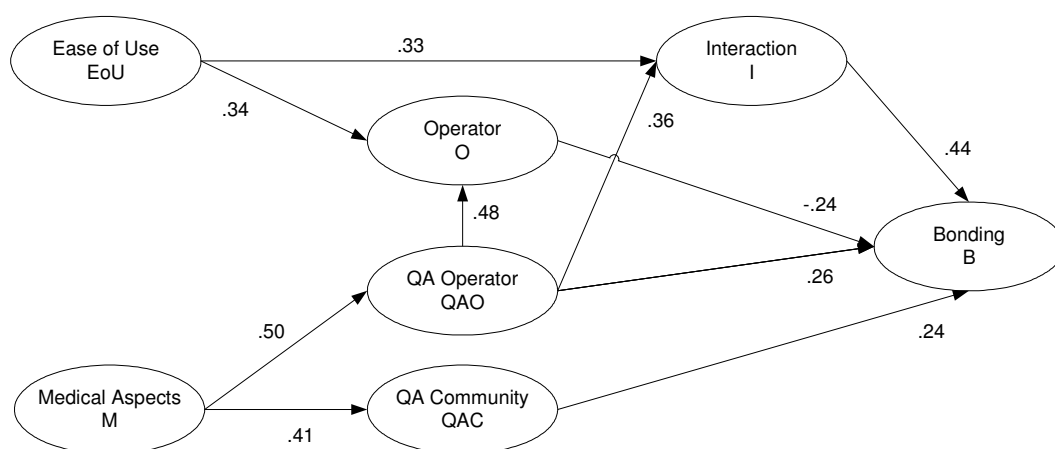
Figure 2: *Structural equation model (members of VCHC)*

Let us explain this model and relate it to examples and theory. All latent variables lead to the latent endogenous variable Bonding (B). Bonding, i.e., the social relations among community members and between community members and the community site distinguish the business model community (Hagel III and Armstrong 1997; Timmers 1998; Wellmann 2001; Hummel and Lechner 2002). Interaction strengthens these social relations (Rheingold 1994) and this is reflected by the model as the direct effect of Interaction (I) to B is the strongest (.44).

The availability of medical information (M) on the site influences B only indirectly via quality assurance of medical information by the community (QAC) and quality assurance of medical information by the operator (QAO). Note that this indirect effect (.25) is as stronger as the one of QAO, QAC and role of the operator (O) inversely. Let us compare this with reality and literature. The typical community site architecture features an "information only" area and little means for interaction with little relation between these two parts. In such an architecture neither of the two parts benefits from the other. It is the interconnection between community and information and the process of establishing a common understanding of the field of interest, a common body of knowledge, common values, and a community that is so important for a community and strengthens the identity of a community and the bonds among members and between members and the community (Hagel III and Armstrong 1997; Preece 2000; Hummel and Lechner 2002; Acton, Golden et al. 2005).

Quality assurance for medical information (for research reports, physicians and treatments) by the community, experience reports, recommendations and ratings could be one way to establish the common understanding and values. In practice, many communities have developed their way of dealing with medical information. Some do not allow medical information to be communicated, some encourage personal experience reports, most VCHC have a strong opinion about origin and treatment of the disease and this again may not be challenged by the members (Dannecker and Lechner 2004). This illustrates that carefully designed e-services are necessary to enable communities to deal with that kind of information that is desired by the members and possible invaluable for patients with chronic diseases.

The role of an operators and its typical job of controlling a community in terms of member satisfaction, member interaction, growth (latent variable O) is not beneficial for the community. Several authors describe the suspicion of communities against controlling (Hagel III and Armstrong 1997) and ways of self-organization (Ginsburg and Weisband 2004).

Interaction, e.g., online and offline events (I) strengthen bonding and ease of use (availability, reaction time and usability of the web site of the community) are prerequisite of good interaction. Again this is mirrored by the path EoU->I->B in Figure 2. An operator that promotes interaction, e.g., through special events can benefit from good medical content (M) and strengthen the bonding of the community (M->QAO->I->B in Figure 2).

This model captures clusters of success factors and the analysis in the previous paragraphs gives an impression which kinds of e-services strengthen which component and the bonding, which is essential for communities. We look in a second step to the ten success factors that are most important according to absolute values to determine which kind of e-services are most promising to develop. Furthermore, we look into the success factors with differences between the members' and operators' view greater than .5 (cf. Figure 1) and the distribution in the components of the research model (cf. Figure 2).

Table 5: *Importance and difference of components due to success factors from members' view compared to operators' view*

	Components						
	O	**B**	**EoU**	**M**	**QAO**	**I**	**QAC**
Number of important factors for members (Top Ten)	0	2	2	**3**	0	0	**3**
Number of success factors with differences greater than .5	0	**1**	0	**1**	**1**	0	**2**

Entries in the first row in Table 5 that are highlighted in gray and boldface indicate that all variables within the component (see Appendix A: Table 9) are part of the ten most important success factors from a members' view. In the second row the highlighted entries indicate that there are different greater than .5 views in importance due to the success factor. We observe again that medical aspects and quality assurance done by the members are the most important. This coincides with our results presented before and also with our results presented in Section 7.

The objective of this first analysis is to find out which success factors are the most relevant for VCHC and the e-services for which there is a demand by members. The next step in our analysis is to look at different target groups within a VCHC to find out which e-services eventually help newly diagnosed and long-term affected people and how to attract and keep members in a community.

## 7.   Target Group Specific Needs and E-Services

We assume that VCHC can be effective in communicating important disease related information and therefore it is desirable to reach and attract patients that just have been diagnosed and are affected for a short time by the disease (newly affected) as well as patients that have been affected for a long time (long-term affected). We also assume that it is desirable to attract visitors and turn them to members and to keep members for a long time within the community. Therefore we look into the differences in demand for e-services between community newbies and experiences community members and between newly affected and long term affected members.

Note that our study indicates no significant correlation between the time the people are affected by a disease and the time the people are member of a community. Let us discuss this. VCHC are a rather new phenomenon compared to the time people are possible affected by a disease. We distinguish between the timeframe regarding the time people are affected by their disease (less than 1 year…more than 20 years) and the time people are a member of the VCHC (less than 3 months…more than 36 months). Note, that this lack of relation between length of community membership and time the people are affected by their disease is an indicator that currently VCHC have problems in attracting newly diagnosed patients and in keeping these patients for a long time. Subsequently, we focus on the members only. Let us analyze the differences between new and experienced members first.

7.1   New vs. Experienced Members in the Community

The interests and needs of members that are new to a community typically differ from interests and needs of long-time members. Keeping new members, activating passive, non contributing members or keeping active members active are considered important goals in community management (Hagel III and Armstrong 1997; Preece 2000).

To determine if there are pair wise associations for the sets of normally distributed variables a "Bivariate Correlations" examination based on "Pearson" was executed. All correlations w.r.t. the time people are member of a VCHC and the success factors are significant at p < .001. In Figure 3, the main difference (>= .2) in success factors between the view of newbies (member less than 3 months) and experienced members (member more than 36 months) are depicted.
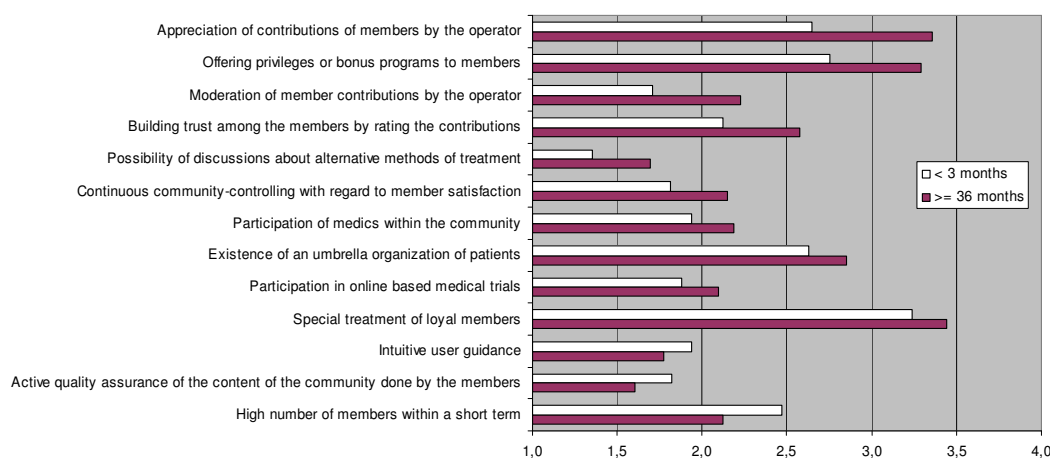
Figure 3: *Main differences in importance to success factors by the view of newbies and experienced members (sorted by difference >= .2)*
(highly agree 1 – highly disagree 5)

Let us discuss first the issues that are more important to newbies than to experienced members. In general, the role of an operator, moderator and medical experts and an umbrella organization is more important for newbies than for experienced members according to the results presented in Figure 3. Experienced members seem to have more trust in community and most likely are more aware of the self-organization processes and the power of the community. Newbies rely more on formal qualifications (medics), distinctive roles (Operator, Moderator) and formal processes (medical trials).

Experienced members are more interested than newbies in other community members (meeting community members offline), usability of the website (Figure 3) and in quality assurance done by community members (Figure 3) and in the number of members of the community. They seem to be more interested in community and seem to have more confidence in what the community can contribute (Figure 3). Note that the bonding to the VCHC is more important to the experienced members than it is to newbies (e.g. "Does the community play a central role").

We conclude that a formal organization with distinctive roles and the presence of medical staff is important for newbies as this signals orientation and safety – for experienced members it is the interaction with other members that is important to them.

In the survey, we asked how important particular e-services are and how much members contribute. First, we notice that the experienced members contribute more often than

newbies. Interaction (I) is important to them, which is also reflected by the higher activity of experienced members within self help groups and the fact, that they know more people in real life. We observe that overall all questions regarding the e-services seem to be more important to experienced members than to newbies.

Table 6: *Top Ten of important factors by newbie and experienced member view*

Important Factors			
Newbies (< 3 months)		**Experienced Members (>= 36 months)**	
Success factor	Ø	**Success factor**	Ø
Handling member data sensitively	1,1765	Handling member data sensitively	1,2273
That people understand you with your problems	1,2941	That people understand you with your problems	1,3881
Possibility of discussions about alternative methods of treatment	1,3529	Stability of the website	1,5152
Push of research within the field of your disease	1,5333	Assistance for new members by experienced members	1,5821
Assistance for new members by experienced members	1,5882	Active quality assurance of the content of the community done by the members	1,6061
Statements of the community about medics	1,5882	Establishing codes of behavior (netiquette/guidelines)	1,6716
Fast reaction time of the website	1,6471	Fast reaction time of the website	1,6970
Offering up-to-date and relevant clinical trials	1,7059	Sustaining neutrality when presenting and selecting offers	1,7000
Statements of the community about medical institutions	1,7059	Statements of the community about medical institutions	1,7121
Moderation of member contributions by the operator	1,7059	The feeling to be in a place at home	1,7424

For newbies as well as experienced members "Handling member data sensitively" and "That people understand them" are the most important factors. Comparing the entries in Table 6 the differences in the needs of newbies and experienced members can be described as follows. For newbies medical as well as quality assurance aspects are in their focus. For experienced members more altruistic and social aspects are important.

7.2 Newly Affected vs. Long-Term Affected Patients

Figure 5 depicts the main differences (>=.2) between the view of newly affected and long-term affected patients. To determine if there are pair wise associations for the sets of normally distributed variables a "Bivariate Correlations" examination based on "Pearson" was executed. All correlations w.r.t. the time people are affected by their disease and the success factors are significant at $p < .001$.
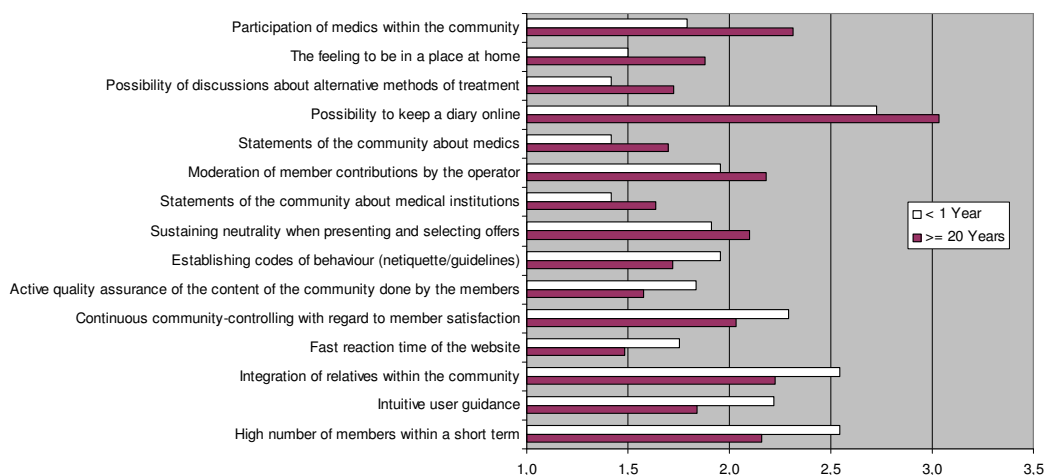
Figure 5: *Main differences in importance to success factors by the view of newly affected vs. Long-term affected members of VCHC (sorted by difference >=.2)*
(highly agree 1 – highly disagree 5)

Let us first discuss the factors that are more important to the people affected less than a year than to people affected for a very long time. We see that information about medical issues by the community, about treatments and medical institutions, and medics is important. Again, as in the previous section we see the importance of medics, and of formal roles within the VCHC (moderator, neutrality of the community). The feeling at home in the virtual community is also important for newly affected members. For members that are affected more than 20 years, community aspects, e.g. netiquette, high number of members, the controlling of a community, the contributions of members as well as technical issues about the website (fast reaction time, usability) are more important.

Table 7: *Top Ten of important factors by newbie and experienced member view*

Important Factors			
Short term affected (< 1 year)		**Long term affected (>= 20 years)**	
Success factor	**∅**	**Success factor**	**∅**
Handling member data sensitively	1,1667	Handling member data sensitively	1,0938
That people understand you with your problems	1,3750	That people understand you with your problems	1,3939
Statements of the community about medics	1,4167	Push of research within the field of your disease	1,4375
Possibility of discussions about alternative methods of treatment	1,4167	That people understand you with your problems	1,4545
Statements of the community about medical institutions	1,4167	Assistance for new members by experienced members	1,4848
Assistance for new members by experienced members	1,4167	Fast reaction time of the website	1,4848
Push of research within the field of your disease	1,5000	Statements of the community about medical institutions	1,6364
Stability of the website	1,6250	Offering up-to-date and relevant clinical trials	1,6563
Offering up-to-date and relevant clinical trials	1,6667	Encouraging interaction between members	1,7879
Participation of medics within the community	1,7917	Arranging regular events	1,9189

For short term as well as long term affected members "Handling member data sensitively" and "That people understand them" are the most important factors. Comparing the entries in Table 7 the differences in the needs of short term affected members and long term affected members can be described as follows. For short term affected members medical as well as quality assurance aspects are in their focus. For long term affected members medical and interaction aspects are important.

7.3 Specialized e-Services

In the previous two subsections we distinguished according to time of membership and the time members are affected by their disease. We observed differences and we conclude that indeed different e-services are necessary to attract new members and to keep members.

We relate these results to our research model. We look into the ten success factors that are most important according to absolute value to each of the four target groups. Table 8 illustrates to which components of our research model these most important success factors belong. Entries that are highlighted in gray and boldface are these entries that fit all variables within the components (see Appendix A: Table 9).

***Table 8:** Classification of members of a VCHC*

Type	Classification	Components						
		O	**B**	**EoU**	**M**	**QAO**	**I**	**QAC**
Time of membership	newbie	1	1	2	**3**			**3**
	experienced		**4**	2	1			**3**
Time affected by disease	newly affected		1	2	**3**		1	**3**
	long term affected	1	1	1	2		**2**	**3**

Note that quality assurance (QAC) is very important to all four target groups as the three success factors that constitute that component are among the top ten success factors. Note furthermore that the relevance of bonding (B) to experienced members. For new members (newbies) and newly affected members medical content (M) is more important. This suggests that medical content attracts new members and good bonding keeps members and interaction is important to long term affected members.

8. Discussion

The objective of our research is to find out which e-services eventually benefit virtual communities of patients. This paper presents results from an empirical study on success factors for virtual communities of patients. Success factors comprise e-services and issues in communication design and community management. The first result is the list of the most important success factors of members and operators. This gives a hint what operators and members would like to have for their communities. The differences between operators and members reflect the current state of art in services for online communities of patients: patients find a lot of medical services important –operators do not and, accordingly, most communities do not dispose of those services. There seem to be quite a misperception of what kinds of services members value from the point of view of operators. The second result is a model that illustrates the role of interaction and the role of medical information for communities. Service that allow a community to establish a common quality standard are important and again, this is an issue where members and operators have different opinions. This again, gives a hint what kinds of services should be implemented. The third result is the specific needs for particular subgroups of a community for services and for community management. We look at the need of new and experienced members and newly affected and long-term affected members. The data sample suggests that health related communities fail to attract the newly diagnosed, that they do not very well in keeping and activating members. We expect that the different groups need different kinds of services. The study gives results on what kind of services the various groups think to be important to them and, in fact different kinds of services are needed for the different status groups.

The results presented in this paper can only partly be generalized to other kinds of communities, since communities differ in service use and the importance of interaction and information for the social network of a community. The results on service use are confirmed by scientific literature and currently a follow up project is developing customized services.

Acknowledgements

References

Acton, T., Golden, W., van der Heijden, H. (2005). "Effects of see-through interfaces on user Acceptance of small-screen information systems." ECIS.

Borgaonkar, M. R., Townson, G., Donnelly, M. (2002). "Providing Disease-Related information worsens Health-Related Quality of Life in Inflammatory Bowel Disease." Inflamm Bowel Disease 8: 264-269.

Borgetto, B. (2004). "Selbsthilfe und Gesundheit - Analysen, Forschungsergebnisse und Perspektiven," Verlag Hans Huber.

Byrne, B. M. (2001). "Structural Equation Modeling with AMOS, Basic Concepts, Applications, and Programming," Lawrence Erlbaum Associates, Inc., Publisher.

Dannecker, A., Lechner, U. (2004). "Virtual Communities with a Mission" in the Health Care Sector. Research Symposium on Emerging Electronic Markets, S. Klein (Editor), Dublin University, Dublin.

Dannecker, A., Lechner, U. (2005). Content driven business models in the Health Care Sector. Research Symposium on Emerging Electronic Markets, Y.-H. Tan (Editor), Department of Economics and Business Administration, Vrije Universiteit Amsterdam, The Netherlands, Amsterdam.

Dannecker, A., Lechner, U. (2006). Success Factors of Communities of Patients. 14th European Conference on Information Systems, Göteborg.

Figallo, C. (1998). "Hosting Web Communities: Building Relationships, Increasing Customer Loyalty, and Maintaining a Competitive Edge," John Wiley & Sons, Inc.

Ginsburg, M., Weisband, S. (2004). A Framework for Virtual Community Business Success: The Case of the Internet Chess Club. 37th Annual Hawaii International Conference on System Sciences (HICSS'04), Hawaii.

Goldschmidt, P. C. (2005). "HIT and MIS: Implications of Health Information Technology and Medical Information Systems." Communications of the ACM 48(10): 69-74.

Hagel III, J., Armstrong, A. G. (1997). "Net gain: expanding markets through virtual communities," Harvard Business School Press.

Hamman, R. (2003). Computernetze als verbindendes Element von Gemeinschaftsnetzen. Virtuelle Gruppen: Charakteristika und Problemdimensionen. U. Thidecke. Wiesbaden, Westdeutscher Verlag. 2: 213-235.

Hulstijn, J., Tan, Y.-H. (2005). Design Aspects of a Personalized Information System about Healthcare Regulations. Research Symposium on Emerging Electronic Markets, Y.-H. Tan (Editor), Department of Economics and Business Administration, Vrije Universiteit Amsterdam, The Netherlands, Amsterdam.

Hummel, J., Lechner, U. (2001). The Community Model of Content Management. Proceedings of the IFIP Conference on Towards The E-Society: E-Commerce, E-Business, E-Government, Kluwer, B.V.: 231-246.

Hummel, J., Lechner, U. (2002). Social Profiles of Virtual Communities. 35th Annual Hawaii International Conference on System Sciences (HICSS'02), R. Sprague (Editor), IEEE Press, Hilton Waikoloa Village.

Janke, K. H., Klump, B., Gregor, M., Meisner, C., Haeuser, W. (2005). "Determinants of life satisfaction in inflammatory bowel disease." Inflamm Bowel Disease 11(3): 272-286.

Kartseva, V., Tan, Y.-H. (2005). Designing Controls for a Marketplace of Health Care services: a Case Study. Research Symposium on Emerging Electronic Markets, Y.-H. Tan (Editor), Department of Economics and Business Administration, Vrije Universiteit Amsterdam, The Netherlands, Amsterdam.

Kennedy, A., Robinson, A., Nelson, E., Rogers, A., Reeves, D., Sculpoher, M., Richardson, G., Thompson, D., Roberts, C. (2003). "A randomised controlled trial to assess the impact of a package comprising a patient-orientated, evidence-based self-help guidebook and patient-centred consultations on disease management and satisfaction in inflammatory bowel disease." Health Technology Assessment 7(28): 140.

Leimeister, J. M., Sidiras, P., Krcmar, H. (2004). Success Factors of Virtual Communities from the Perspective of Members and Operators: An Empirical Study. 37th Annual Hawaii International Conference on System Sciences (HICSS'04), IEEE Press.

McKnight, D. H., Choudhury, V., Kacmar, C. (2002). "The impact of initial consumer trust on intentions to transact with a web site: a trust building model." The Journal of Strategic Information Systems 11(3-4): 297-323.

McLure Wasko, M., Faraj, S. (2005). "Why Should I Share? Examining Social Capital and Knowledge Contribution in Electronic Networks of Practice." MIS Quarterly 29(1): 35-57.

Nonnecke, B., Preece, J. (2001). Why Lurkers Lurk. Americas Conference on Information Systems, D. Strong and D. Straub (Editors), Omnipress, Boston.

Nonnecke, B., Preece, J., Andrews, D. (2004). "What Lurkers and Posters Think of Each Other." 37th Annual Hawaii International Conference on System Sciences (HICSS'04).

Pratt, W., Unruh, K., Civan, A., Skeels, M. (2006). "Personal Health Information Management." Communications of the ACM 49(1): 51-55.

Preece, J. (2000). "Online Communities: Designing Usability and Supporting Socialbilty," John Wiley & Sons, Inc.

Preece, J. (2004). "Etiquette online: from nice to necessary." Communications of the ACM 47(4): 56-61.

Rheingold, H. (1994). "Virtual Community: Homesteading on the Electronic Frontier," HarperTrade.

Schubert, P. (1999). "Virtuelle Transaktionsgemeinschaften im Electronic Commerce," Josef Eul Verlag.

Suler, J. (2000). Bringing Online and Offline Living Together: The Integration Principle. The Psychology of Cyberspace. J. Suler, www.rider.edu/suler/psycyber/integrate.html (2005).

Timmers, P. (1998). "Business Models for Electronic Markets." EM - Electronic Markets. The International Journal of Electronic Markets and Business Media 3: 3-8.

Wellmann, B. (2001). "Computer networks as social networks." Science 293(14): 2031--2034.

Whittaker, I., O`Day (1997). Widening the web. Workshop report on the theory and practice of physical and Network communities. Report from ACM CHI (Computer Human Interaction).

Yahoo. (2005). "Health & Wellness." Retrieved 29.04.2005, 2005, from http://health.dir.groups.yahoo.com/dir/Health___Wellness/.

Appendix A: Factor Analysis

An explorative factor analysis was executed to find evidence of convergent and discriminated validity. Table 6 summarizes the factor loadings for varimax orthogonal seven-factor solution using a principal components analysis.

Table 9: *Summary of factor loadings for varimax orthogonal seven-factor solution*

	Factor loads								
	O	**B**	**EoU**	**M**	**QAO**	**I**	**QAC**	**∅**	**Diff**
Cronbach-Alpha	.823	.746	.774	.712	.653	.768	.824		
Continuous community-controlling with regard to member growth	.878							2.84	-0.07
Continuous community-controlling with regard to the frequency of visit	.861							2.90	0.01
Continuous community-controlling with regard to member satisfaction	.624							2.15	-0.15
Special treatment of loyal members	.577							3.47	0.03
Appreciation of contributions of members by the operator	.509							2.99	0.31
Does the VCHC play a central role within your life		.754						2.67	-0.86
Satisfaction with the evolution of your VCHC		.698						2.37	-0.66
The feeling to be in a place at home		.686						1.70	0.07
That people understand you with your problems		.565						1.40	-0.16
Do you ask questions within the community you won't ask a physician		.550						3.27	0.63
Do you write articles within the forum		.515						4.01	-0.16
Fast reaction time of the website			.802					1.79	-0.26
Stability of the website			.787					1.65	-0.22
Intuitive user guidance			.727					2.01	-0.33
Personalized page design of the community			.589					2.52	0.15
Participation in online based medical trials				.766				2.08	0.03
Push of research within the field of your disease				.651				1.57	0.60
Offering up-to-date and relevant clinical trials				.630				1.80	0.39
Existence of an umbrella organization of patients					.639			2.70	0.85
Building trust among the members by rating the contributions					.598			2.45	0.22
Moderation of member contributions by the operator					.504			2.14	0.39
Supporting the community by regular real-world meetings						.695		2.49	0.09
Arranging regular events						.689		2.17	0.13
Statements of the community about medical institutions							.887	1.57	0.78
Statements of the community about medics							.861	1.57	0.78
Possibility of discussions about alternative methods of treatment							.655	1.65	0.21

All cronbach-alpha values (see Table 9) for each measure of the estimated values show that the reliability of the construct is within an acceptable range.

The total explained variance is 70 percent. Each item with a factor load less than .50 or loaded on another factor greater than .40 were suppressed. All variables are normally distributed. On the left hand side in Table 9 the different variables are listed.

In the second column from the right side, the mean based on the operator view is shown. Recall (see Table 1) that a value of 2.0 or less indicates agreement or strong agreement (value of 1) to that statement.

The last column on the right side shows the difference between the mean based on the members view to the mean value of the operators view. That means the value has to be added to the mean value of the members view to get the mean value of the operators view. E.g. regarding the entry "Statements of the community about medics" with the mean value in Table 9 by 1.57 and the difference 0.78 leads to the mean value 2.35 of the operators view.