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ACCEPTANCE AND UTILITY OF A SYSTEMATICALLY DESIGNED VIRTUAL COMMUNITY FOR CANCER PATIENTS

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Abstract. Virtual Communities (VCs) offer ubiquitous access to information and exchange possibilities for people in similar circumstances. This is especially valuable for patients with chronic / life-threatening diseases as they exhibit strong needs for information and interaction. Grounded on the preceding findings of the analysis on the user-centric construction of the VC *krebsgemeinschaft.de*, this article describes the evaluation of the underlying design elements and success factors by assessing the user's acceptance and usage of the site. The results obtained empirically substantiated insights into the systematic development and operation of VCs in general and for a sub-group of cancer patients in the German healthcare system in particular.

Keywords: Virtual Community, patients, community-building, evaluation, community design.

General conditions for cancer patients and potentials of Virtual Communities

Cancer is the second most frequent cause of death in Germany with approximately 338000 newly diagnosed people yearly (Deutsche Krebshilfe 2003). It is astonishing that until 2001 few information or interactive sites for cancer patients could be found on the German-speaking internet (Daum et al. 2001). With this background, the COSMOS¹ -research project developed, introduced, and operated a Virtual Community (VC) for cancer affected persons.

This article focuses on the evaluation of acceptance and usage of the site by intended users. The basis for this project was preliminary work on the systematic and user-orientated design of the Virtual Community *krebsgemeinschaft.de* (Arnold/Leimeister/Krcmar 2003; Leimeister 2004; Leimeister/Daum/Krcmar 2002). After a brief description of the situation of patients, we outline the potentials of a VC for this user group. We then summarise the central design elements as well as the specific characteristics of these elements for the case of *krebsgemeinschaft.de*. Further, the acceptance and utility of the site are evaluated and discussed. The paper concludes with an analysis of the implications of the findings.

The situation of cancer patients

Most people react to a diagnosis of cancer with shock and disbelief. Not only the diagnosis but the ensuing treatment as well cause disturbances in daily routines and devastate plans for the future. Provoked by a life-threatening diagnosis, the patient often falls into a psychological crisis. This crisis causes a strong demand for sense-making processes concerning the new situation (Madara 1997).

A desire to seek and attain information on cancer and its treatment is one method used by cancer patients to assist them and those close to them to make sense and therefore cope with a devastating situation. The search for information is only one aspect of the coping-process: patients also seek emotional support from similarly affected persons. Hence, the desire for interaction can emerge.

Information needs

Cancer patients often exhibit a high demand for information after diagnosis or during therapy (Bilodeau/Degner 1996; Brockopp et al. 1989; Derdiarian 1987; Hinds/Streater/Mood 1995; McCaughan/Thompson 1995; Mills/Sullivan 1999).

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This demand can result from the asymmetric distribution of information between physician and patient.

The type of requested information has been shown by recent research on the characteristics of the demands of cancer patients. Kaminski et al. (2001), for example, identified strong interest in obtaining information pertaining to various areas including the effects of cancer on life, work, family or sexuality (for similar findings see (Bilodeau/Degner 1996; Leydon et al. 2000; McCaughan/Thompson 1995; Shuyler/Knight 2003)). The attending physician is often overstrained by the patient's drive for information. Survey research on patients and self-help groups as well as analyses of patients requests to medical service providers (Bahrs/Klingenberg 1995; Hiller 2001; Ruprecht 1998) have shown that patients are not only interested in medical competence in the classical sense, but to a great extent in the physicians' ability to communicate and relay human interest in dealing with the unique problems of the individual patient (Hiller 2001). Mutual acceptance, emotional care, empathy, a holistic treatment as well as higher quality and better cooperation between all parties involved in the treatment process are mentioned as potential fields for improvement.

Demand for interaction

One can often sense patient's inner wish for empathy and interpersonal interaction. Interaction with others with similar backgrounds and disease plays an important role for patients (Forbiger 2001). Their demands are not necessarily restricted to scientific facts, but also to sharing first hand experiences that are derived from personal symptoms and interpreted for the individual situation (c.f. (Ferber 1987; Mills/Sullivan 1999; Moeller 1996; SEKIS 2000)). In order to cope with the new situation or to discuss treatment possibilities, the affected person needs one or more interlocutors. There exists an intense interest in similar cases and the experiences of others (Bilodeau/Degner 1996; Lieberman et al. 2003; Manaszewicz/Williamson/McKemmish 2002).

Cancer patients do not always search for partners as sources of information or interaction. But those who do actively cope with their situation through interaction and information seeking are reported as experiencing less depression, fear, and complaining behaviour, are better socially integrated and often make better progress in their healing process (McPherson/Higginson/Hearn 2001; Zemore/Shepel 1987)).

Legal framework for internet-based medical services in Germany

The public health system in Germany is a highly regulated sector. Laws and rules of professional conduct regulate how health care workers act. Medical information services on the internet are subject to the general legislation of internet services. It is well known, however, that there are few rules and

guidelines that regulate the content of medically-oriented web sites (Dierks/Nitz/Grau 2003, p. 95).

Although general, the following concepts provide a rough legal framework for web-based medical information services: legal liability is assumed for the content of external websites linked to other parties' content, consideration of limits and boundaries placed on the medical profession's limits and boundaries in terms of the differentiation between information and advice, aspects of data security in the context of telematic services as well as specifics for the circulation of scientific information to laypersons. This legal framework influences patient internet-services in Germany as it requires for user- and usage-agreements as well as disclaimers. Furthermore, computer-mediated individual medical advisory services are illegal. Only physicians are allowed to offer this service after a face-to-face consultation has taken place. Therefore, general information services are the only type of patient information sites that are legally permitted by German law.

Potentials of Virtual Communities for patients

Patient services are commonly bound to specific opening hours. Centers or offices that are potential sources of information have specified times of operation and require that the patient or family member physically present him- or herself to obtain the desired information. Similarly, conventional support-groups meet at scheduled times and places (mostly in city centres) and interaction with members is dependent on physical presence. Internet services have advantages in that they are always available and easily accessible.

Up-to-datedness, anonymity and needs-based coverage of patient information

The timely relevance of information in the internet is often far better than in other media forms. Considering the possible importance of health-related information on a subjective or an objective professional level, this medium can bare a crucial advantage. New research findings and developments are available much faster through the internet. Due to the higher perceived anonymity of the internet (c.f. Döring 2003), one will probably find users to be more open with their comments, especially concerning difficult topics such as life-threatening diseases or traditionally taboo topics. A quote from Anja Forbringer, a cancer survivor, illustrates this point: *„It is not easy for me to speak [fact to face] about the »problem cancer«. The more anonymous internet is a great help”*.

Web-based information provides patients or information seekers with the opportunity to pick and choose which information they need and when. But due to the different usage of the provided information depending on the media used, different requirements arise for online texts than for paper-based ones, a challenge for Virtual Communities that want to provide edited and quality-assured informations for members.

Interactivity, empathy and empowering patients

The internet with its different services offers multi-lateral interaction possibilities. It integrates a feedback channel and provides collaborative mass communication: users can simultaneously be senders and receivers of information (Döring 2003, p. 41f.; Rafaeli/LaRose 1993).

Interaction within Virtual Communities often allows the development of empathy between members (Preece 1999; 2000; 2001) as well as emotional integration into a community of peers. Empathy can be characterized by three criteria (Levenson/Ruef 1992, p. 234): a) *knowing* how the other person feels, b) *feeling* what another person feels and c) *answering/acting according to this feeling* for the misery/woe of the other person. A sense of community is considered a fundamental ingredient of a working VC (Blanchard/Markus 2002) and it is often based on the existence of empathy among the members.

Interaction between members of a VC generates an information pool of credibility as members contribute their often extensive knowledge and experience to the pool (Schubert 1999, p. 100), (Peppers/Rogers 1997, p. 244). The existence of such VCs can lead to an information asymmetry in favour of the members and contribute to the empowerment of patients. The members of a VC might reach a higher market potential and simultaneously a higher market power (Lechner/Schmid 2001) (Schubert 1999, p. 99) for patients.

Central design elements of a VC for patients – the case of *krebsgemeinschaft.de*

Important design elements for a VC for patients are the presentation of content (information services), the functionalities, the usability and the accessibility of the system as well as the use of trust building components (Leimeister 2004).

In the following we summarize the design elements and their characteristics for the VC *krebsgemeinschaft.de*, a VC for breast cancer patients in the German-speaking internet.

Information services

The major challenge in the area of information services lies in the amount of editorial and quality-assured content on the topic breast cancer for this VC. There were two major challenges: the transformation of medical terminology to an understandable language and the implementation of a structure for this complex subject. As a result of iterative development and several rounds of discussions with experts (for background information see also (Arnold/Leimeister/Krcmar 2003)) the following categorisation of the content was developed and ranked according to the expected relevance for the users:

a) *cancer treatment* (therapy, managing treatment side effects); b) *identifying cancer* (early recognition, diagnostic methods) c) *cancer research* (study results, facts and figures) d) *living with cancer* (sports, nutrition, family, sexuality) and e) *experiences with cancer* (reports of affected persons).

The division into main- and sub-categories was intended to help the user to understand the provided information in a structured way, to support cognitive processing and to minimize the cognitive load.

Functionalities

The functionalities section offers a discussion forum / bulletin board, a “ask the expert” section, a contact search for members, and chat modules. Further services provided on member’s personalized start page include: individual interaction services such as an internal mailing-system, a guestbook, buddy-lists and awareness-functions such as “friends online”, “users chatting” or “number of members of the krebsgemeinschaft.de” (see Fig 1).

The discussion forum/bulletin board enables an asynchronic exchange between members. It not only supports communication, but also supports the process of members getting to know one other. This, then, supports the creation and the cultivation of a sense of a community (Blanchard/Markus 2002).

The service “ask an expert” is a modified form of a discussion forum where users post their questions and designated experts in that area provide answers. The service is organized in periodic cycles; each cycle has a featured focus or theme and a prominent expert. This system reduces the work-load for the experts and the service is easier to organize. Users of this service can easily make inquiries without time pressures.

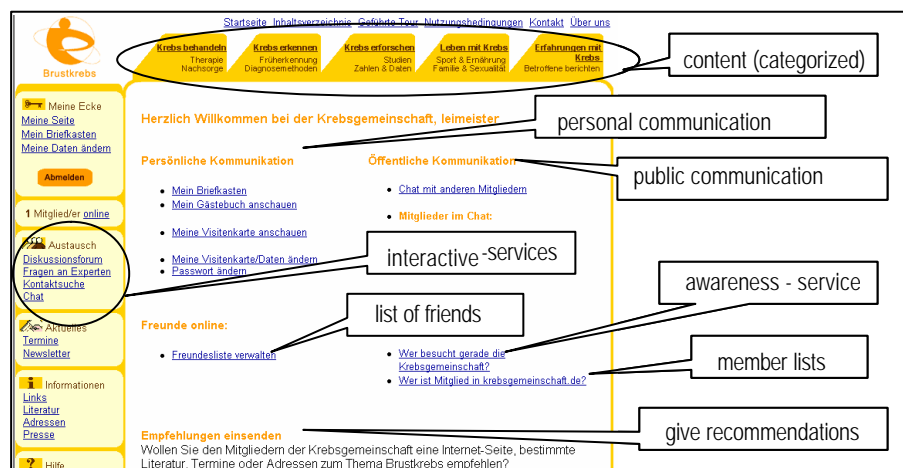


Figure 1: Information and interaction services as well as the personalized starting page for members on krebsgemeinschaft.de (Source: (Leimeister 2004, p. 201)).

The *contact search* aims at supporting the members in finding people in similar situations and/or with similar interests. The service is designed to offer an easy possibility for contacting other members. This service also fosters direct interaction between members and enhances a sense of community.

The *chat* offers the possibility to get in contact with other members simultaneously. It is a synchronic real-time communication which requires at least two participants. To increase the probability of meeting other users in the chat room, fixed chat hours were established.

Usability

Potential users of services on the internet decide within seconds whether or not they want to use services; thus, the usability of services and sites is of major importance to potential users. Aspects such as layout, colour, graphics, and scripts play an important role. These aspects are often subsumed under the term usability. Usability is always context- and usage-specific. That is the reason why there are no generally valid rules for creating usability. Usability and the overall impression have a strong influence on whether websites appear trustworthy and credible (Fogg et al. 2002). From the various usability-principles (compare e.g. (Mannhartsperger/Linder/Zellhofer 2003, p. 17ff)), one can derive the following meta-principles:

Adequacy of a task: a dialogue with a system is adequate if it is supporting the execution of the task of the user without burdening him with unnecessary details (e.g. from the dialogue system).

Conformity with expectations: a system's behaviour conforms to the expectations if each element or each part of the system represents that part of the design and content that the user expects.

Consistency: a uniform appearance of a system within one context is named „consistency“. Consistency is crucial for usability because the user can rely on already learned patterns and does not have to adapt to new systems. Consistency is one of the most important usability principles (Mayhew 1992) and leads to usability (Spolsky 2001), (Nielsen 2002).

Visibility: Well designed human-machine-interfaces have easily visible control elements. Each control element (knob, button, etc.) controls optimally only one function (Norman 1988, 1992).

Accessibility

As the internet ensures the transmission of information in form of text, it can contribute to overcome physical defects of users. The usage of one sense organ can be replaced by the usage of another (WEBforALL 2004a). This issue is especially important for target groups such as cancer patients whose often treatment-induced physical restrictions limit mobility.

Different kind of barriers can exist on websites. They are created by the use of specific configurations and designs and might restrict handicapped people from using the services.

Since May 1st 2002, German government web sites as well as all graphical user interfaces provided by them must be designed to allow persons with handicaps to use them unrestrictedly. A barrier free internet site is easily read and navigated with tools available for handicapped users. To achieve this, providers have developed design guidelines for barrier free internet sites (e.g. (WEBforALL 2004b)).

Trust supporting components

In addition to user friendly interfaces and useful services, trustworthiness is an important success factor for a VC. A set of trust-supporting components consists of a transparent provider concept (who is providing the service and what is his motivation to do so), an adequate access right concept and reasonable role models (which tasks and roles exist within the VC, who is responsible for them and which set of authorization does each actor have), an anonymity concept (each user should be able to determine independently how much of his private data he wants to share with other users), and the usage of trust-seals. For this last component, the trust seal promoted by the German Federal Health Ministry *afgis* (Health Information System Action Forum, <http://www.afgis.de/index.php?lang=e>) is used for *krebsgemeinschaft.de*. For further information concerning the development and design of the trust supporting components see (Ebner/Leimeister/Krcmar 2004; Leimeister/Ebner/Krcmar 2005, Leimeister 2004).

Acceptance and usage of *krebsgemeinschaft.de*

Evaluation criteria and methods

To evaluate the efficacy of the design components used during the development of *krebsgemeinschaft.de* it was necessary to identify criteria for the success of each single component and the sum of all components. Measuring success and consequently identifying a cause-effect chain for single components is difficult as the effect of each individual component on the user cannot be easily isolated. Frequently, only the sum of all actions and influences is assessable. Figure 1 illustrates the previously mentioned design components and their cumulative effect on the acceptance and usage of *krebsgemeinschaft.de*.

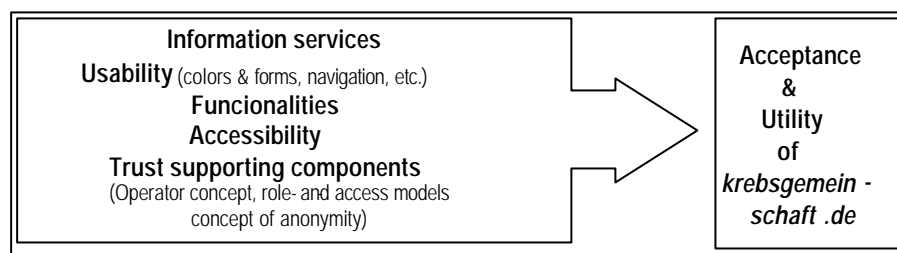


Figure 1: Intended cause-effect chain between design components and usage and utility of *krebsgemeinschaft.de*

Specific indicators for the success of VCs can be found on different levels of abstraction, although one has to state a lack of systematic approaches and operational suggestions for measuring the success of VCs. We will consequently apply evaluation techniques from both classical social research and online research, especially log file analyses, online surveys, document analysis and observations. These techniques will be applied to the case of the VC *krebsgemeinschaft.de*. All data refer to the period from 19.08.02 to 22.05.03 unless otherwise specified. We begin with the quantitative analysis of the server log files, and then we will analyze the conducted online member surveys. Finally several archive analyses will be conducted and observations will be analysed.

Empirical findings

Performance measures for the evaluation of interactive elements within the community

The core of a VC is the interaction of the members which mainly occurs in chat rooms or discussion forums/bulletin boards. The following criteria were used to measure “member-to-member interaction” (adapted from Cothrel 2000, p. 18):

Key figures for the assessment of the number of visitors (average values per week)		
(1)	Total number of visits per week	899
(2)	Total number of page impressions per week	4627
Criteria for the discussion forum (averages per month)		
	Number of users in discussion forum per month	275
1.	Number of active users (writing messages) per month	22
2.	Number of passive users (read only) per month	253
(1)	Number of articles	
a.	Number of articles – posted per month	11,6
b.	Number of articles – read per month	Ca. 550
c.	Number of replies posted per month	25,3
Criteria for the chat (average values per month)		
(1)	Number of users in chat	190 (different IPs per month)
a.	Number of active users (writing messages)	190
b.	Number of passive users (read only)	n.n.
(2)	Number of messages	n.n.
(3)	Number of users connected	n.n.

Table 1: Key data for the usage of *krebsgemeinschaft.de* during the period 08/2002-05/2003.

Log-file-analyses and their purely quantitative values are insufficient to evaluate a VC. A small number of active users (like the one which has evolved in *krebsgemeinschaft.de*) contribute more to the „life“ of a community than a greater number of passive users, so called „lurkers“ (Nonnecke/Preece 2000). For that reason we used qualitative analyses in form of member surveys, observations and archive analyses. All empirical findings are to be compared and triangulated.

Usage of services

We focused on the usage of the different components of *krebsgemeinschaft.de*. We started with analyses of the usage of both the edited and quality assured content. After that we analysed the users' behaviour concerning the interaction services (chat, forum, ask experts, contact search).

Usage of the edited content – content categories (top level): The graphical presentation and positioning of the content on the website is presented in figure 1. The content categories and their arrangement were chosen in correspondence with their expected importance as found in other media and services for cancer patients. The top-level content categories (designed as index-cards) with the categories *cancer treatment*, *identifying cancer*, *cancer research*, *living with cancer* and *experiences with cancer* were arranged in seceding order from left to right.

For all content categories (index cards) a similar development of the user numbers could be observed. The user numbers declined after the first weeks followed by a ground-building process on a more or less stable level. Relatively high values could be seen in the last month of observation in the categories „*cancer treatment*“ and „*living with cancer*“ (contradicting the assumption that living with cancer would be ranked 4 in interest). Accordingly, these topics seemed to be of exceptional interest for the users of *krebsgemeinschaft.de*. As the editorial content had not changed for a longer period of time, it could be assumed that frequent visitors had saturated their demand for information on the pages and omitted them during later visits. Only a few “new” members registered in the VC in the analysed period. This could provide an explanation for the declining user numbers in this section. The total decline could be a first hint for the existence of an individual member life-cycle that correlates with an individual information-demand-curve, which could depend e.g. on the phase of illness or the time elapsed since diagnosis.

Interaction services: The analysis of the development of the single interaction services showed clearly that the contact search was rarely used. The reason for this might be that following the launch of the platform, a group building process among new members had started. In consequence, many users did not have the problem of finding others since they were already integrated into a newly

emerging group. On the other hand, a reason could be the poor implementation of the service. Within the framework of the surveys it was mentioned by several users that the contact search was not working as it should or more precisely it functioned too slowly.

Discussion forum/bulletin board: The discussion forum was a frequently used service of *krebbsgemeinschaft.de*. In total, 367 entries were posted during the evaluation period. Of these, 114 were new threads and 253 were replies to these threads. This means, that there were more than an average of two replies per request whereas the number of answers varied between 0 (often no answer was expected) and 9. Most answers were directly connected to the question. Rarely did a discussion emerge that was unrelated to the initial posting. To evaluate which issues were discussed in the discussion forum, a content analysis of the threads and replies was conducted. Two main thematic blocs could be identified: 1) postings that stated a rather factual demand for information, and 2) emotional postings seeking emotional support from other members and demonstrated a wish for emotional integration into a community as well as for empathy. Often the two categories could not be separated as some of the requests for information were posed in an emotional context. Examples were questions about hair loss after chemotherapy or breast reconstruction following mastectomy.

All in all, the discussion forum was mainly used to share individual experiences with others and to learn from others' experiences. When applying this categorisation the major part of the threads has to be assigned to the „factual“ category, but a high percentage of these postings also bared the already mentioned emotional aspects. Of interest, very intimate and personal postings were made in the forum. Members spoke honestly and openly about their feelings and personal experiences. However, the content generated during the first month after the launch was made by only a few members who were very intensively engaged in *krebbsgemeinschaft.de*.

Nicpages and guestbooks: The anonymity concept of *krebbsgemeinschaft.de* offered the members the possibility to decide on their own which personal data they wanted to reveal to the other members of the community by means of their personal nicpage (non-registered users/visitors do not see any member data). The members have four choices of anonymity levels: *Show nothing* (other members will see the note: „The member does not want to show his/her data.“), *anonymized* (displayed: user name, state, status, kind of relationship to the illness, date of diagnosis, type of cancer, stage of the disease, form of therapy, hobbies, interests), *anonymized but show all to friends* (members of a users buddy list can see all available user data, other members see the data available on the anonymized level), and finally the level *show all* (displayed: all available user data). The nicpage is situated above the guestbook of the member and can be accessed by clicking on the user name at any place within the VC.

In May 2003 there were 634 active guestbooks in *krebsgemeinschaft.de*. 273 (43.1%) chose „show nothing“, 272 (42.9%) „anonymized“, 9 (1.4%) „generally anonymized and all to friends“, and 80 (12.6%) displayed all data to all members of the VC. A strong correlation between the degree of anonymity and the number of entries in the guestbook could be identified: While 273 owners of a guestbook with the anonymity level “show nothing” only received 30 entries; the 272 guestbooks with the nicpage configuration “anonymized” received 217 entries. The 80 guestbooks in the “show all”category made up for a total of 383 entries and the 9 guestbooks with the level “anonymized but show all to friends” had 3 entries.

These data seems to indicate that openness could be a major precondition for the functioning of the VC. The more data other members can see, the more entries they themselves post. If members show openness and trust by revealing their identity, they will be rewarded by receiving more postings in their guestbooks. This is supported by the construct of “reciprocity“ (Preece 1999, 2000; Preece/Maloney-Krichmar 2003). According to this principle, the provision of information to the community is a catalyst for receiving information and reaction from the community or more precisely from other members.

It is important to annotate that the distribution of the guestbook entries was asymmetric. On the one hand a large part of the guestbook did not get any entries and on the other hand some very active members in *krebsgemeinschaft.de* had more than 40 entries.

This situation, as well as the fact that many of the entries in the discussion forum were posted by few members, indicates that a small and very active community of members had emerged. This group contributed very much to the life within the community and *krebsgemeinschaft.de* seemed to play a vital role in their real lives.

The relationships of these active members to each other seemed to be very close and the interaction between them exceeded the limits of the VC and reached into their everyday “real” lives. These members cared very much about the situation and the problems of other active members and tried to support each other.

Member surveys: Acceptance and utility of *krebsgemeinschaft.de*

From quantitative analyses one can not easily derive conclusions about the individual usage and usability of the platform. It is even more difficult to gain insights into the utility for users created by their usage of a single specific service within *krebsgemeinschaft.de*. For the purpose of this article, we define usage as the frequency of usage of specific services as declared by the respondent. Following the design components of the VC, the usage behaviour was analysed for both information and interaction services. Both spheres were addressed with closed- and open-ended questions. We define utility as the subjective impression of the respondents concerning advantages they received from using

krebsgemeinschaft.de. This aspect was also addressed in member surveys using open- and closed-ended questions.

Overall evaluation: All in all the participants in the survey assessed the design of *krebsgemeinschaft.de* as positive (figure 2). This is not surprising when considering the fact that most respondents were using the service intensely. A frequent usage itself can be seen as a positive assessment of the service.

On average, the users agreed that the site was clearly structured, easily readable, and that desired content could be found easily. Especially the coloured design was perceived as positive. Users were always aware of the author of the content. The loading time and the technical performance of the platform were rated less favourably.

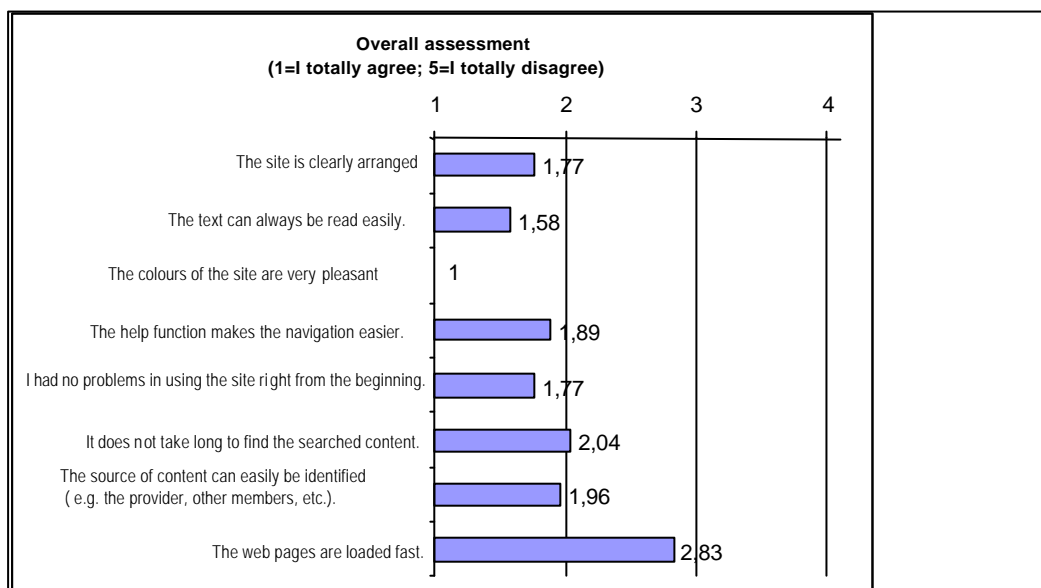


Figure 2: Overall evaluation of *krebsgemeinschaft.de* (n=27)

Correlation between usage of different services and duration of membership in *krebsgemeinschaft.de*: The data shows a relation between the length of membership and usage behaviour concerning the usage of information services. 55.5% of the people who were members for less than six months were using the information services „each time” they visited the VC. In comparison, only 40% of those persons with memberships older than 6 months used these pages this frequently. A conclusion could be that the subjective importance of the information service declines with increasing length of membership.

An even clearer correlation exists between the „duration of membership” and the usage of interactive services. The usage of these services increased significantly during membership. 38.5% of those who were members for more than 6 months used them “each time” whereas none of the users with less than 6 months membership chose that answer.

The findings are indicators for an individual membership life cycle, which becomes manifest in different usage levels of the system. It can be assumed that those new members were faced with a high demand for “hard facts” as their diagnosis was more recent than that of older members. As time elapsed the users often developed far reaching knowledge and therefore the need to use the information services became less important. The usage of the interactive services shows an inverse development. The longer the person was a member, the more intense the community feeling was and the more intense the usage of the interactive services became.

Utility: The analysis of the direct question about the felt utility of *krebbsgemeinschaft.de* revealed two major reasons for using the VC: On the one hand the site offered professional knowledge about cancer and on the other, a perhaps more important aspect, users established contact to other persons in similar situations. Respondents declared that social relationships and empathy could easily develop. These findings are similar to the results of the analysis of the forum postings. Furthermore the members said they could easily integrate emotionally in a community and support one another. The establishment of “real-life” meetings reinforces this point.

The following answer to the question “how has the membership in *krebbsgemeinschaft.de* changed your situation” exemplifies the importance of the service:

„The interchange with others is very beneficial for me. Especially right after the diagnosis friends and family assume that life goes on as before. That’s wrong!! Of course you don’t want to speak all the time about your (bad) mood and your medical status and somehow no one wants to hear it all the time. Therefore the interchange with other patients is important: You get the mental support you need and it is good to know you’re not the only person struggling with such a situation. And it is very impressing and supportive to read how other women can cope with the situation. That resurrects your own will to fight and helps you to cope with the healing process or medical set-backs.”

Trust-Support: During the conception and implementation of *krebbsgemeinschaft.de*, trust supporting elements were designed and implemented in the VC (Leimeister/Ebner/Krcmar 2005). The process of trust building should be supported by these components in order to contribute to the establishment of a community. To evaluate the effect of trust-supporting components, an online-survey, guided by the following research questions, was conducted among the members:

- (1) Do the members of *krebbsgemeinschaft.de* assign a positive perceived competence and a positive perceived goodwill to the operators?
- (2) Do the members of *krebbsgemeinschaft.de* trust the operators of the community and their provided content?

- (3) Do the members of *krebsgemeinschaft.de* assign a positive perceived competence and a positive perceived goodwill to the other members?
- (4) Do the members of *krebsgemeinschaft.de* trust the other members and the user-generated content?

The results (for further details on the survey, results, thresholds, etc. see Leimeister/Ebner/Krcmar 2005) seem to confirm the effect of these trust building components. Members were asked about both the trust in the providers of *krebsgemeinschaft.de* (especially in their expertise) and the trust in the other members (especially in their benevolence) seemed both to be high.

The behaviour of the questioned members fits well to this finding: They were prepared to use information provided by the community as well as to provide their own knowledge and experiences to other members. Therewith they stated clearly that they trusted that their data was being handled in a secure manner and that the provided information was of high quality. Furthermore it could be proved that a large proportion of the questioned members were acting according to statements made in the surveys (for further details see (Leimeister 2004).

Discussion and Conclusion

The evaluation of *krebsgemeinschaft.de* revealed various findings. First of all, *krebsgemeinschaft.de* can be rated as a successful VC. The registration numbers have increased; there was a stable highly active core community and an extended community with passive members (lurkers). Inside the core community the reciprocity-principle was working very vividly in terms of the exchange of information, empathy and support. The communication was characterized by a high degree of empathy and trust towards both the provider and the other members. The conception of trust supporting components seemed to have lead to the desired outcome.

The number of violations against the rules of the community or incidents that could be categorized as rude or impolite was very low. The active members were very content with the social interaction within the VC. The fact that most members who were involved in the VC from day one still actively participated in the community after 24 months advocated for strong loyalty ties to *krebsgemeinschaft.de*.

Concerning the demand-coverage of the community-platform, most members seemed to be satisfied, though different functions were rated quite differently. Furthermore it could be seen that the design (e.g. the GUI and the design of functionalities) was generally assessed as user-friendly. However, the surveys showed as well, that some of the VCs characteristics were not known and therefore not used by members (e.g. the anonymity concept or the contact search), additionally these features were not working satisfactorily during the period of analysis. Moreover results revealed that the technical reliability of the platform

was more important to the members than sophisticated services or functionalities. The technical equipment was not the limiting factor but the conception of a service was much more important for its success. This became obvious through the very different usage of the service „ask experts“: By means of shorter reply times, high quality and easily understood answers, the usefulness and frequency of usage of the service was increased immensely. This conclusion was derived from user feedback (approx. 100 emails) to the community management.

The user feedback in the board and in the mails to the community management also showed the central role of qualitative valuable content as an asset for attracting potential users. Another critical success factor in building this VC was the role of the community management which ensured activity and attractiveness until the critical mass of users had been reached.

The evaluation showed furthermore that there was a shift in the information and interaction demands depending on membership duration. The desire for interaction and the appreciation of this feature seemed to increase correspondingly with length of membership.

Consequences for further research – First of all, the findings of this explorative research should be compared with research findings from other types of VCs in order to improve the capacity of the results. A quantitative research model could be developed on the basis of these research findings and used to expand the theoretical foundations for Virtual Communities.

Additionally there are several chances and challenges for VCs created by new technical possibilities. Ubiquitous accesses to VCs through mobile digital devices as well as new (mobile or rather context sensitive) services for VCs are potentially very rewarding (e.g. an emergency system for cancer patients with a locating service or a mobile pill reminder). The relevance of these innovations for VCs cannot yet be assessed.

Furthermore, there is a need for research on the role and tasks of community management. There is a lack of substantial work on administration tools (especially if a community manager acts as administrator for several communities) that efficiently and effectively support management.

The analysis of social interactions within VCs and the effects on the social network of the members have yet to be fully investigated. Research on the exact utility of healthcare-oriented VCs seems to be especially promising when focussing on the measurement of the VC's influences on the perceived quality of life and the costs of treatment.

Recapitulating, the results of this article demonstrate empirical proof that the chosen approaches for user-centric development, implementation and operation of a VC for cancer patients within the German healthcare system lead to a success as demonstrated by high ratings given to the VC by users. Results convey a rich understanding of multi-dependent influences on Virtual Communities in general and contribute to a better understanding of community building for patients.

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