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Potentials and Benefits of Patient Communities from a German Perspective

Helmut Krcmar, Jan Marco Leimeister

Information Systems (I17), Technische Universität München
Boltzmannstr.3, 85748 Garching, Germany
{krcmar; leimeister}@in.tum.de

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 (an online community for cancer patients in the German-speaking internet) and the evaluation of the underlying design elements we summarise our findings on potentials and benefits of patient communities in Germany.

1 General conditions for cancer patients and potentials of Virtual Communities[1]

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 COSMOS[2] -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, et al., 2003; Leimeister, 2004; Leimeister, et al., 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.

1.1 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.

1.1.1 Information needs

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

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[1] The results presented in section 1 & 2 have been extracted from Leimeister, J.M., and Krcmar, H. "Acceptance and utility of a systematically designed virtual community for cancer patients," *Proceedings of the Communities &Technology 2005*, Milan, 2005, .

[2] The research project COSMOS (Community Online Services and Mobile Solutions) is a joint project of the Technische Universität München and O2 (Germany) GmbH & Co. OHG. The project is supported by the Ministry of Education and Research FKZ 01 HW 0107 –0110. Further information can be found under http://www.cosmos-community.org

Degner, 1996; Leydon, et al., 2000; McCaughan and Thompson, 1995; Shuyler and 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 and 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.

1.1.2 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 and 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 and Degner, 1996; Lieberman, et al., 2003; Manaszewicz, et al., 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, et al., 2001; Zemore and Shepel, 1987; Ziegler, et al., 1986; Ziegler, et al., 1984)).

1.2 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, et al., 2003).

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.

2 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.

2.1 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 (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.

2.2 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) (Rafaeli and LaRose, 1993).

Interaction within Virtual Communities often allows the development of empathy between members (1999; 2000; 2001) as well as emotional integration into a community of peers. Empathy can be characterized by three criteria (Levenson and Ruef, 1992): 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 and 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), (Peppers and Rogers, 1997). 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 and Schmid, 2001) (Schubert, 1999) for patients.

3 The case krebsgemeinschaft.de

The offer www.krebsgemeinschaft.de is a VC for cancer patients that has been developed as part of the research project COSMOS (Community Online Services and Mobile Soultions). The objective of the project is to develop, design and operate Virtual Communities for different user groups and research the process of designing Virtual Communities systematically and to develop theoretically sound and empirically verified guidelines for successful Community Engineering. Starting in January 2001 the project developed and piloted two VCs for cancer patients, one for breast cancer patients and one for leukemia with currently over 1300 registered users and new registrations daily. The offer for the target group breast cancer patients was introduced to a broader public on August 18th 2002.

3.1 Strucure of the krebsgemeinschaft.de

krebsgemeinschaft.de can be divided in two major areas: information and interaction services. The information services are located on top of the page (see Fig. 1, “Centrally provided quality assured content”).

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, et al., 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.

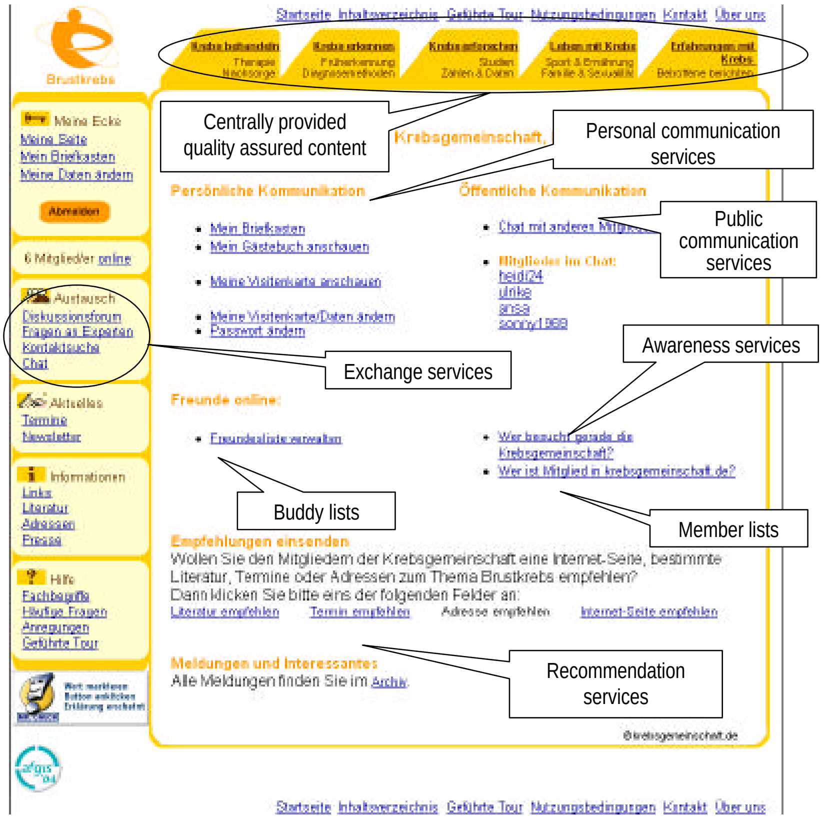
The other major section of krebsgemeinschaft.de can be summarised under exchange services. There are a discussion forum / bulletin board, a “ask the expert” section, a contact search for members, and chat modules. Further services provided on member’s personalized start page include: individual interaction 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 “Exchange services”).

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 and 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.

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.



Wollen Sie den Mitgliedern der Krebsgemeinschaft eine Internet-Seite, bestimmte Literatur, Termine oder Adressen zum Thema Brustkrebs empfehlen?
Dann klicken Sie bitte eins der folgenden Felder an:

Alle Meldungen finden Sie im Archiv.

Figure 1: Personalized starting page for members on krebsgemeinschaft.de

3.2 Findings from over 2 years of operation of a VC for cancer patients

Evaluating krebsgemeinschaft.de (for further details see (Leimeister, 2004)) we came to identify 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 among members (as to giving and taking in the community) 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 members seemed to trust both in the operators and the other members (Leimeister, et al., 2005).

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 (for further details see (Leimeister and Krcmar, 2005), 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, member surveys showed as well, that some of the VCs characteristics were not known and therefore not used by members (e.g. 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 feedack (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.

Virtual Communities for patients offer potentials and benefits to their members. The previously mentioned aspects of independence of time and space, anonymity, up-to-datedness, needs-based coverage of patient information needs as well as the aspects of interactivity, empathy and empowering patients could be verified in the case of krebsgemeinschaft.de.

Additional potentials and benefits can be identified for other stakeholders. Operators can use patient communities to show expertise and responsibility for the targeted patient group. Potential benefits range from positive image effects (e. g. as to corporate responsibility) to a better supply of patients and therefore positive factors on their perceived quality of life. Hospitals, health information providers and health insurances could realise the potentials of patient communities if operated neutral and responsible.

4 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. We need to expand the empirical knowledge on and theoretical foundations for patient 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.

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.

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