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Virtual Communities in Health Care: The Case of “krebsgemeinschaft.de”

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ABSTRACT

This paper focuses on the process of designing, implementing and evaluating a community platform for cancer patients. Following an introduction to the situation of cancer patients in Germany we summarize our findings on cancer patients' demands for trustworthy information as well as their need for interaction with peers in similar situations. On this basis we describe the process of translating socio-technical needs into system requirements and the steps undertaken to develop a functioning community platform for cancer patients. We combine a generic iterative process model for systems' development with elements of prototyping towards an engineering process model for community platforms for cancer patients. We then describe the evaluation framework and first results.

Keywords

Community engineering, web-based system development, user involvement, requirement engineering, website design, cancer patients, health care, virtual communities in health care, evaluation framework

1. INTRODUCTION

Community platforms on the Internet have great potential to serve ubiquitous information and interaction needs. Such an omnipresent demand exists, for instance, in healthcare when patients develop a desire for information and supportive communication which exceeds what is offered by either the treating physician and/or health care institutions.

1.1 Cancer and the Health Care System in Germany

The number of new cancer incidents in Germany sums up to 164900 male and 173400 female cases per year [1]. According to the report of the National Advisory Council to the German Government [15] the treatment of cancer patients in Germany leaves room for improvement. The relationship between physician and patient is often described as being paternalistic. A situation which does not lend itself to patient participation in decision-making. In order to obtain quality care and the appropriate treatment in today's health care system, patients must be active and competent consumers. Suitable information available at the

right time is crucial in aiding decision-making. "Recent surveys show that 40-54% of patients access medical information via the internet and that this information effects their choice of treatment" [22]. Medical information is not all that is needed or sought on the internet. "E-Health offers patients databases of medical information, but patients want to hear about treatments and how to deal with problems from other patients" [25, xvi].

1.2 Cancer Patients' Needs for Information and Interaction

Patients' needs and demands for information often increase after a diagnosis of a disease or during medical treatment [27]. Patients seek information in order to help them make sense of a given diagnosis or to assist them in making decisions about treatment. In addition to demands for factual information, patients seek emotional support and the opportunity to communicate with other patients experiencing similar physical and emotional symptoms. The need for information and interaction plays an important role in dealing emotionally with a disease, an assumption backed by research on self help groups [for an overview see 16]. The diversity of over 100 types of cancer, the complexity of treatment modalities coupled with a hardly manageable professional and lay literature makes coping with the informational, emotional and medical aspects of cancer extremely difficult and tiresome.

The evolution of virtual communities has been a positive step in meeting the emotional and educational needs of cancer patients without overtaxing their already limited physical and psychological resources.

2. Requirements Engineering and the Development of Community Platforms

2.1 The Dilemma of the Requirements Collection

Designing and building virtual communities has been the focus of science and practice for a number of years [for an overview see 26]. However there is a paucity of empirically tested process models for the development of community platforms in general and the health care sector specifically.

Although software development is usually done within an organizational framework, many of the developed information systems do not match the needs of the target users. Orphaned community platforms on the internet underline this mismatch. Traditionally, system development takes place in a linear manner, starting with the conception phase and ending with the phase of the death or substitution of the system. Alternative models have been developed as the linear model contains many dysfunctional aspects [5,7]. The internet as a possible environment for an information system targeted to heterogeneous user groups demands more flexibility and, at the same time, has a high degree of uncertainty.

In 1995, the European Software Process Improvement Training Initiative (ESPITI) surveyed problems within the software engineering process. The two most commonly identified problems were 'requirements specification' and 'managing customer requirements' [21, p.8]. According to Conallen [8, p.89] requirements are defined as "a statement of what the system should do. The collection of all of the requirements of the system is the requirements specification". Little attention is paid to the alteration or adaptation of already acquired requirements during later phases of development. Therefore, it is essential to pay particular attention to the collection and adaptation of requirements and to involve the target user in early stages of the software development cycle. The requirements engineering approach attempts to take into account these key elements. Requirements engineering is defined by the IEEE Std. 610.12 as "(1) the process of studying user needs to arrive at a definition of [...] requirements; and (2) the process of studying and refining [...] requirements" [17, p. 17]. This definition incorporates the understanding that requirements can (and do) change during the development process.

In order to develop a platform that meets users' needs, requirements engineering addresses essential success factors for system development; it is therefore, a suitable framework for the development of a community platform. Numerous activities and methods reported in the literature guide and support the discovery of requirements [17]. The questions remain, are they applicable for our purpose and can they be combined with a process model for system development?

Following an extensive review and consideration of published approaches, we were unable to secure an appropriate model that combined an applicable process for the development of a platform for the Web [for a discussion of Web Engineering see 23, 14] and the inclusion of requirements engineering activities that involve intense participation of targeted users.

2.2 Requirements deducted from prior Field Studies

Prior field studies pertaining to the information and interaction needs of cancer patients [20] and the examination of existing web information platforms on the German language market [9] lead to some general requirements. Starting from with these requirements, the process model has to integrate parallel activities of requirements engineering to provide the flexibility needed for the development of a web based platform. Therefore an applicable process model should:

- be an iterative process,
- be able to adapt to changes of requirements during the development process,

- include several mock-ups and prototypes,
- be easy to apply especially for small and medium size projects,
- be applicable for different types of services (information as well as interaction),
- involve users from the beginning.

In the following we suggest a process model that meets these preconditions.

2.3 Towards a Community Platform Engineering Process (CoPEP)

The heart of the CoPEP process model is an iterative process adapted from the generic spiral process model [7, p.26]. It is combined with elements of prototyping. In comparison to the original spiral model, a stronger focus is placed on scenario discussions, the display of mock-ups and prototypes, and the active involvement of users. Requirements are collected and adapted within each iteration. The process model CoPEP (Community Platform Engineering Process) was used during the development of the platform *krebsgemeinschaft.de* for breast cancer patients. Beginning with the planning phase, the activities for the respective iterations are scheduled. Afterwards the needed input for the tasks is analysed and the appropriate requirements are either deducted from the prior field studies (iteration 1) or simultaneously collected through user involvement (iteration 2-4). The rendered part of the system is evaluated after the engineering phase is completed. Using the deducted general requirements (see chapter 2.2), the translation of the socio-technical needs into system design is done iteration by iteration with the assistance of users.

After cycling through the phases a total of four times, the pilot system was operative and could be introduced to the broader public. System development, however, doesn't cease with the launch of the platform. A Web Platform is a dynamic system; the demands of the users continuously change and therefore the requirements change with usage. Continual refinement is necessary [23]. With the launch of the system begins the next set of iterations. Enhancements and supplements to existing functionalities are discussed in scenarios and iteratively added onto the system following the CoPEP-model.

2.4 User Involvement

CoPEP counters the danger of fixating incorrect requirements during the initial phases by involving end users early on in the development cycle. Visualization of parts of the end product through mock-ups, scenario discussion and prototyping induce a high level of transparency. General requirements get more detailed as the development process progresses and mistakes can be redefined. The targeted users often unfamiliar with the use of the internet or information systems in general. The proposed community platform was somewhat difficult for them to envision. It was also difficult for them to transfer their needs into a concrete design of a web site from scratch. Further, their medical state prohibited prolonged and unrestricted access to them as collaborative partners. In order to meet the substantial claim of user involvement from the very beginning, representatives for the target users were substituted as consultants for the project [for similar findings 12]. The role of target group representatives is to take up various positions upon the system until there are mock-ups or prototypes functioning as visualization that can be

presented to the intended end users. We used a group of various stake-holders as representatives in order to work with as many perspectives on the system as possible [11]. Once the content for the platform is outlined and the case scenarios are conceptualised (in our case at the end of the third iteration) the target users can get involved more easily. At this point in development, the target users are confronted with the intermediate result as a basis for further design, adaptation and detailing.

3. Preliminary Results

3.1 The development process using Copep

Better and more concrete results were achieved through the use of visualization methods during the analysis and evaluation phases of the development. Visualisation allowed the participants and especially the targeted users to better comprehend the concept and therefore indicate to us possible problems to be solved.

The communication structure continuously changed during the development phases. Each involved group had their “own language” which caused difficulties in communication. Starting with a ‘many to many’ communication behaviour, after a while the interaction involved one or two individuals who functioned as intermediaries between the content supplier, the graphic designer, the representatives and the technical staff. We recommend that each development team contain at least one person who assumes the role of intermediary.

Although there was an ongoing discussion and rating of the benefits of a chat functionality on the platform, the actual usage of this functionality was a surprise for the development team. The scenario analysis and rating resulted in a low score for a chat room as the experts indicated that elderly women would be reluctant to use this form of personal communication. The patients themselves indicated that they would rather use the telephone for synchronous communication. The pilot system therefore offered a sparse version of chat only. However, over time we registered a growing usage. Patients started to realise the advantages and finally asked during a feedback session for an upgrading of the functionality and a larger window so that more people could take part in a chat session. This demonstrates that continuous user involvement and feedback cycles as proposed with CoPEP are of great importance in keeping up with the adaptation of requirements.

Besides these aspects the following lessons learnt from the case krebsgemeinschaft.de can be derived:

- (1) Quality assurance of content is crucial: Available content on cancer is very extensive and therefore a standardized quality assurance process is necessary. This makes qualified (medical) partners with competence and high quality content necessary.
- (2) Community management is equally essential. It is time-critical with fast answers required and content-critical with extensive knowledge on e.g. alternative therapies needed.
- (3) Usability is important
- (4) Personal data is very sensitive. Anonymity might help to overcome users’ inhibition. We therefore developed a 4-level anonymity concept (show nothing, anonymous, partly anonymous, show all) as well as an extended Role concept within the Community: 6 roles (unregistered, user, superuser, expert, community manager, content manager, administrator).

3.2 The Community Platform

Krebsgemeinschaft.de was launched in August 2002. Figure 1 shows the design of the community with its different sections.

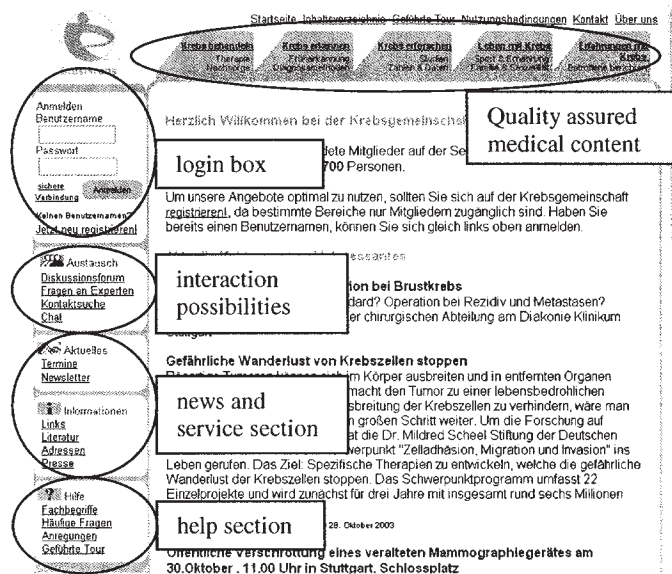


Figure 1: Home Page of www.krebsgemeinschaft.de

3.3 Evaluation Framework

An evaluation framework has been developed based on Schwabe’s evaluation model [28], which results in three levels of evaluation (see also table 1).

On the level “management of introduction” it is important that the platform reaches cancer patients, the potential users. Only then can there be changes in the information seeking and interaction behaviour of the patients. For the evaluation all factors that influence the platform need to be considered. The activities of all people involved are recorded daily.

If the management of introduction is successful it leads to the usage of the virtual community. There, the following data is of special interest: number of members, kind of persons (patients, friends, etc.), time, duration and frequency of usage, activity on the platform as well as what kind of services are used.

Thirdly data needs to be gathered about the changes in information and interaction behaviour as well as the user’s perception.

Table 1: levels of evaluation and data collection methods

data collection levels	survey/questionnaires	observation	analyses of documents	log files	group discussion
management of introduction	X	X	-	-	X
usage	X	-	X	X	X
information and interaction behaviour	-	-	X	X	X

3.4 Findings

During management of introduction we distributed a questionnaire at one event during “European week against cancer”, 2001 and in self-help-groups. We asked the patients what kind of services they use to get information, if they want to interact with others, if they use mobile phones, etc.. The questionnaire was answered by 116 participants (return rate 23%). 37% of women and 31% of men agreed that they want to look for information on the Internet. 29% of women and 44% of men did use the Internet already. 44% of men and 29% of women wanted to communicate more with other patients [20]. The results confirmed that the majority of cancer patients has a strong need for information and interaction possibilities with other patients.

The registration data from the breast cancer community is shown in figure 3. The community officially launched on August 19th, 2002. At the beginning there were many registrations due to press releases, etc.. In November and December 2002 registrations decreased. On January there was a peak with 73 new registrations. The period February to June looks like a stagnation phase. Reasons for this need to be evaluated.

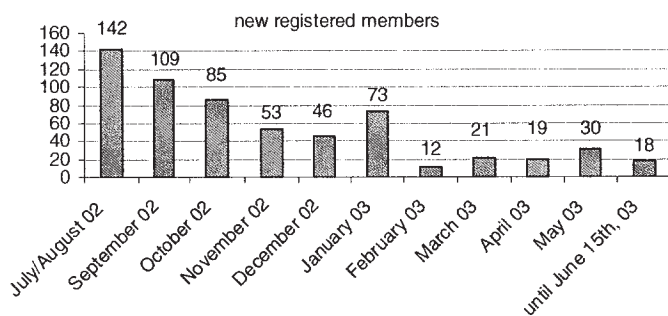


Figure 2: Registration of new members per month

As of June 2003, the breast cancer community has 609 registered users, 81% women, 15% men, 4% ambiguous. The age of illness in breast cancer is 63 years with 46.000 new incidences per year in Germany, thereof 19000 under 60 years old. The survival rate is 73% [2].

There is a lot of interaction in the discussion board between the community members. Many of them are young (between 20 and 55), often with children. The majority is about 40 years old. The members interact about different kind of topics. The majority of contributions concern topics like fear (of recidivism, hair loss, etc.), rehabilitation possibilities, etc.. Other topics like postings of events or happy birthday wishes receive less reaction. In addition, questions about medical information are less, possibly because quality assured information is already provided on the website.

An analyses of 20 power users, that is those members with the longest time online since the launch of the platform, shows, that of them 15 display their date of birth and ten show a picture on their virtual business card. On average the 20 power users have been members of the community for 13 month, are born in 1961 (42 years old) and were diagnosed in 2001 (two years ago). One of these power user is a man, looking for information for his wife. The death of one these power users in November 2003 was a shock for the community. One of the power users sent a request to

the provider of the community, if the next “ask the expert” theme could be how to handle the fear of death.

The analysis of a first online questionnaire in June 2003 with the topic trust was answered by n=32 registered users. 31 members provided their username although they did not need to do it. This could be seen as a sign of trust into the provider. 91% were patients, the rest were relatives. The majority (59%) was under treatment, none had not yet received treatment and 19% were in remission. 50% were members of the community for more than 6 months, 25% less than 1 month and 12,5% respectively for 1-3 or 4-6 months at a time when the community had been online for ten months. 47% of the members visited the community several times a week.

According to the same questionnaire the discussion board is used very often. 59% of the members state that they read the threads every time and 28% very often when they are in the community. But only 31% of them wrote threads themselves occasionally and 28% seldom.

The main reasons why members use krebsgemeinschaft.de are to exchange experiences with others. 31% reply rate that reason as totally agree or strongly agree (38%). The statement that they use the community to seek advice or how to behave in a certain situation was agreed by 25% totally and 47% strongly. Many members stated that they used it to share their knowledge with others (25% and 41%) or to seek information (28% and 47%).

Since the potential users have not been able to express their demands in great details in advance – at least not in technical language - we used a focus group session to collect requirements (group I in table 2). After having developed a running prototype, we conducted another two sessions (group II-1 and II-2). This time, we invited members of a ‘sports after cancer’ group. These group discussions took place in front of computers which had the system running. Consequently these sessions were more of an evaluation type than the focus group before. For this group we record some of the results: We had expected the service ‘Ask-the-expert’ to get a very high score. Indeed, out of 25 possible points (5 participants) it gained 10 in one group and 16 out of 45 points in the other group. This shows that ask the expert is a feature that patients want to have in order to satisfy their information needs.

Table 2: Overview of conducted group discussions

data collection objects	group discussion
management of introduction	group I: focus group with 6 breast cancer patients brainstorming of potential services age: 55 – 62
usage	group II: focus group discussions with 6 and 10 breast cancer patients for task analysis
	group II - 1 age: 47 – 77
	group II - 2 age: 34 – 74

Log files are being recorded during the usage and for the information and interaction behaviour. During the first six months online the page most often used was the start page (31%), followed by the discussion board (8%) and information about treatment (4%). With 3% the categories living with cancer, meet

the expert, experiences with cancer, cancer indication, guided tour and help followed.

The guest book is a service used very often. 41% read their guest book every time and 28% most of the times. The guest books of krebsgemeinschaft.de are used differently than anticipated, because members use it more for personal communication than to post messages or make comments. A more detailed analysis of guest books is shown in figure 2. The individual guest book is displayed together with the business card on everyone's page. In May 2003 there were 634 guest books on the platform. Thereof 273 members (43%) have chosen not to show any data except their user name; these members together received only 30 postings in their guest books. 281 out of 634 members (44%) displayed their personal data on the anonymous level and received 220 postings. About 80 members (13%) are displaying all of their personal data on their business card but together they received 383 postings. And a few, very active members had more than 50 postings in their guest book.

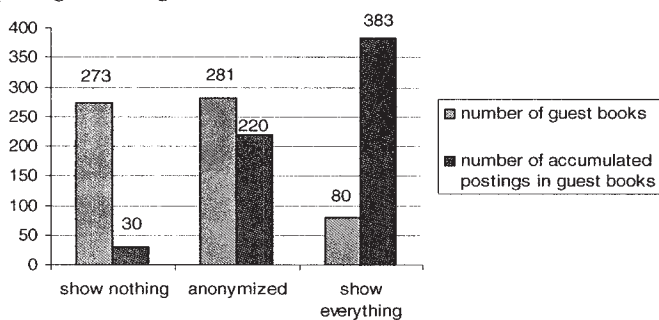


Figure 3: Guest book postings and status of anonymity

Until here we described data from a breast cancer community. In a comparison to a second community for leukaemia patients, which has been launched in May 2003. The average age of illness in leukaemia is 61 years for men and 64 for women, the survival rate 42%.

Some interesting differences concerning the activity of community members, new registrations and possibly related to gender can be found.

The field studies were performed made with breast cancer patients (because there are more patients to carry out ethnographical studies). Therefore we built a prototype in accordance with the needs of the breast cancer patients. The specific needs of the leukaemia patients have not been evaluated in advance – a possible reason why the leukaemia community is lacking in membership and interaction.

In the leukaemia community 55% of all registered members are men, 44% women and 1% is ambiguous. In November 2003 there were 160 registered members. According [2] more than 10000 people in Germany fall ill with leukaemia per year, thereof 53% men and 47% women. This gender relation corresponds with the ratio of the registered members. There are four major types of leukaemia which are very different according to age of illness, treatment, survival rate, etc.. Therefore the membership of the leukaemia community is more heterogeneous than the one for breast cancer. Also, leukaemia community members are less active than the one with breast cancer, which maybe related to gender. Some gender studies show that women are more likely to

communicate and to look for health related information in the Internet [13].

The “Ask the expert”-service as well as the informational content of the website is used by these patients, not the discussion board. A possible explanation could be that there are more information and less interaction needs by leukaemia patients.

4. CONCLUSIONS

The previous has reported first results from an ongoing study.

The empirical data and the different evaluation methods give us the possibility to evaluate the similarities and differences of the two communities. We assume, that there are different success and influencing factors such as type of cancer, gender, age and additionally external factors like a competitive community with a first movers advantage.

To analyse these factors, further data will be collected. Especially data collection will focus on the changes in the information and interaction behaviour of our community members as well as their perceptions.

We expect to be able to report more findings also about aspects of mobile community usage.

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