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The role of virtual communities for the social network of cancer patients

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ABSTRACT

This study investigates the determinants and effects of virtual communities on the development of social relationships within the social network of cancer patients. Influencing factors on the formation of virtual relationships and their effect in the form of social assistance are researched. Following an explorative approach it is examined whether online communities meet their theoretical potential to provide an environment where social relationships can be established that help cancer patients to cope with their situation. Deduced from these results recommendations for patients using online communities and providers administrating online communities are outlined.

Keywords

Virtual Community, Virtual Relationship, Cancer Patient, Social Network, Design Guidelines.

INTRODUCTION

This research was triggered by the situation of cancer patients in Germany. This situation is negatively influenced by two key components: lacking support from the public healthcare system and problems regarding the societal interaction and acceptance of cancer patients. This proves especially problematic as, to achieve an adequate medical support of cancer patients, it is important to serve both their informational as well as their emotional needs. To meet these needs the social support that patients receive through their social network plays a central role (Eysenbach, Powell, Englesakis, Rizo and Stern, 2004). This support positively affects the process of adjusting to the new situation, the well-being of the patients and their attitude in coping with the disease. But the existing social relationships of a cancer patient are not always able to fulfil the task of providing the necessary support (Holland and Holahan, 2003). In many cases social relationships break apart under the burden of the disease. New relationships have to be established to cover the need for social interaction. Besides real-world self-help groups, cancer-related virtual communities have the potential to offer an environment where these relationships can be established.

This study analyzes the role that cancer-related virtual communities play in supporting the development of social relationships in the social network of cancer patients. Furthermore, the role of social relationships that emerged through the use of online communities is examined.

FORMULATION OF RESEARCH QUESTIONS

Background: Web-Based Services for Cancer Patients

According to a 2002 W3B study, German-language websites related to healthcare are a growing segment (Fittkau and Maaß, 2002). In 2003, 24% of the adult population in Germany consulted the internet to find health-related information (Spadaro 2003). In addition to pure informational websites, numerous offerings exist that enable their users to interact with each other by means such as mailing lists, newsgroups or chat rooms (Bader, 2000). A study conducted by Daum and Krcmar shows that interaction services are becoming more popular on cancer-related websites: In 2001 they found that most German cancer-

related websites are purely informational, whereas in 2002 they discovered that more and more websites support interaction services: 18% of the websites offer a bulletin board or an online forum and chat functionalities are included in 5% of the websites (Daum and Krcmar, 2002). These numbers show the growing importance of health-related online offerings in general and cancer-related online interaction services in the German internet in specific. All the more important becomes the question whether these offerings meet their theoretical potential to support their users in coping with their situation.

Online Communities and Virtual Relationships

Before looking at previous studies investigating the potential of online communities to establish social relationships there, it is important to define the two key concepts used in this research: Online communities and virtual relationships. As there is no common agreement on one specific definition of online communities, for the purpose of this study they are defined using some of the key aspects that are repeatedly mentioned (Doering, 2000; Rheingold, 2000):

- Meeting and interaction of people
- connected by a specific interest
- by means of a technical platform
- where they have the chance to establish social relationships.

Social relationships are characterized by a repeated interaction between two persons whereas the individual interaction is influenced by previous interactions as well as the expectation of future interactions (Doering, 2003). To differentiate between virtual and real-world relationships the place of the first interaction is used (Park and Roberts, 1997): A virtual relationship is a relationship where the first contact took place online; a real-world relationship is a relationship where the first contact took place offline.

Especially during the early research on computer-mediated communication and web-based interaction services numerous scholars questioned whether the characteristics of computer-mediated communication allow social relationships to be established in a virtual environment at all (Parks and Floyd, 1996). However, both the experience of numerous users of online interaction services and the results of several studies in this field of research document that it is possible to establish social relationships in online communities (Rheingold, 2000; Rosson, 1999). For example Park and Floyd come to the conclusion that the emergence of social relationships through online services is common and widespread among its users. But, they also discover that relationships which are initiated by virtual interaction mostly are not kept exclusively within a virtual environment, but are migrated to the real world (Parks and Floyd, 1996). Laying the foundation for the current study two research questions are deduced from these insights transferring them to the specific situation of cancer-related online communities:

RQ1: *Do cancer patients establish social relationships through cancer-related online communities?*

RQ2: *Are social relationships of cancer patients that are initiated virtually transferred to the real world?*

To address these two questions participants in this study were firstly asked to describe up to three persons who are important to them to talk to about their disease and whom they got to know via a cancer-related online community. Secondly, they were asked which means of communication (online and/or offline) they use to cultivate the relationship.

Selected Influencing Factors on the Development of Virtual Relationships

As mentioned above online communities provide a platform for their users to establish social relationships there. However, not all users of such services take advantage of this possibility. Subsequently, the question arises which factors influence whether a person establishes social relationships via online interaction services or not. Parks and Floyd come to the conclusion that socio-demographic characteristics hardly influence the socialising behaviour of users of such online services (Parks and Floyd, 1996). However, it might be possible that this result is due to the type of researched interaction service, as for example Wellman and Gulia mention: „The Net is only one of many ways in which the same people may interact. It is not a separate reality. People bring to their online interactions such baggage as their gender, stage in life, cycle, cultural milieu, socio-economic status, and offline connection with others.” (Wellman and Gulia, 2001). Therefore, this study analyses whether socio-demographic factors influence the development of virtual relationships among cancer patients. In addition, the question is addressed whether the type of cancer influences whether cancer patients establish virtual relationships or not, as it can be assumed that persons suffering from uncommon types of cancer might rather turn to the internet to exchange information about their disease than people with widely-spread types of cancer. Hence, the third research question reads as follows:

RQ3: *Do socio-demographical factors and the type of the disease influence the development of virtual relationships of cancer patients?*

According to Parks and Floyd the length of time a certain online offer is used and the frequency of usage are the best indicators on whether users of online services develop virtual relationships or not (Parks and Floyd, 1996). This finding is also confirmed by Wright (Wright, 1999, 2000). Furthermore, Nonnecke, Preece and Andrews observe that active members of online communities who post in boards (poster) develop stronger ties to the community than members who just read postings (lurker) (Nonnecke, Preece and Andrews, 2004). Thereupon research question four can be deduced:

RQ4: *Do characteristics of internet usage influence the development of virtual relationships?*

According to the uses-and-gratification approach in media usage research, people choose to use a certain type of media because they expect some kind of gratification from that usage (Burkart, 1998). Hence, it can be concluded that the motive of the actual internet usage, the gratification they expect, influences the internet usage behaviour. This study focuses on the question whether different motives of internet usage have an influence on the development of virtual relationships of cancer patients (Wright, 2002).

RQ5: *Do motives of internet usage influence the development of virtual relationships of cancer patients?*

Based on a study conducted by Wright, motives of internet usage as defined by Papacharissi and Rubin, are used for the purpose of this study: Interpersonal utility (defined by statements such as “to help other” and “to belong to a group”), pass time (defined by statements such as “when I have nothing better to do” and “to occupy my time”) and information seeking (defined by statements such as “to look for information” and “new way to do research”) (Papacharissi, and Rubin, 2000).

Wright highlights the role of perceived advantages and disadvantages of computer-mediated communication (CMC) on whether users of online self-help groups experience them as fulfilling or not (Wright, 2002). Eventually these advantages and disadvantages do not only influence whether virtual relationships are perceived as fulfilling but, whether a person establishes online relationships at all. Hereon, the question to be addressed in this study is:

RQ6: *Do the perceived advantages and disadvantages of CMC influence the development of virtual relationships of cancer patients?*

Advantages and disadvantages identified by Wright through a survey among participants of online self-help groups are used as a foundation for addressing this question (Wright, 2000). These advantages and disadvantages are complemented by information gained through other studies. The advantages addressed in this study are: Access to a wide-range of different persons and to persons who made similar experiences; chance to interact with persons with whom only loose social ties exist (Turner, 2001), independency from space- and time; chance to communicate anonymously (Wright, 2000, 2002) and non-existing time-pressure to answer questions (Maloney-Krichmar and Preece 2003; Turner, Grube and Meyers 2001). Disadvantages addressed in this study are: Absence of human expressions (e.g. gestures), missing possibility for direct contact (e.g. hugging), behaviour of other users that is perceived negatively (e.g. hostile messages) and temporally delayed feedback (Wright, 2002).

Social Support Received through Virtual Relationships

In the last step of this study the potential “result” of virtual relationships defined as social support is researched. Wright revealed that people join online self-help groups for the same reasons and therefore for the same problems for which people join real-world self-help groups (Wright, 1999). According to Turner, the support received through online interaction services is perceived as helpful as support provided by real-world contact persons (Turner et al., 2001). Positive effects of online support are also mentioned by Gustafson and Maloney-Krichmar. Both studies report that members of online self-help groups superiorly cope with information about their disease due to the received support; furthermore, their emotional situation improves (Gustafson, Hawkins, Pingree, McTavish, Arora, Mendenhall, Cella, Serlin, Apantaku, Stewart and Salner, 2001; Maloney-Krichmar and Preece, 2003). A study conducted by Loader et al. identifies emotional as well as informational support as types of support provided by virtual relationships (Loader, Muncer, Burrows, Pleace and Nettleton, 2002). This leads to research question seven:

RQ7: *Which types of support are provided through virtual relationships of cancer patients?*

Consolidating all seven research questions the following research model emerges (Figure 1):

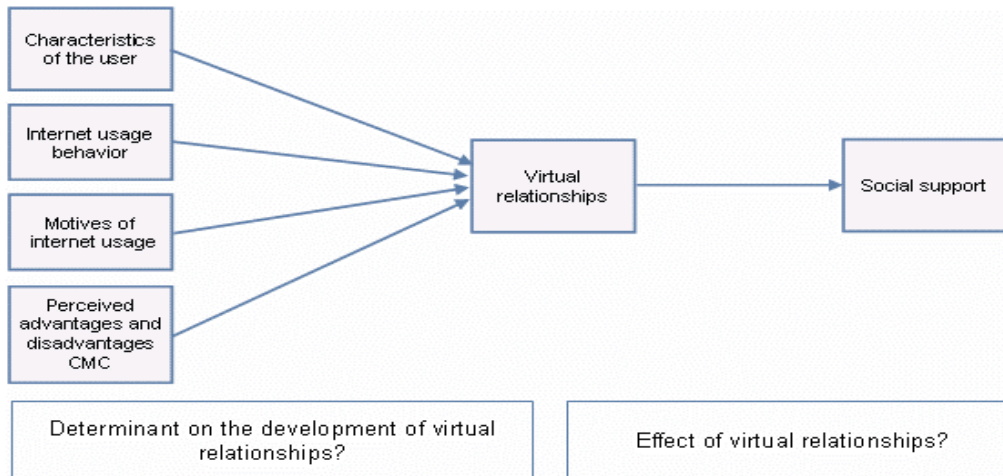


Figure 1. Research model

METHOD

An explorative research approach was chosen to allow the necessary openness for unexpected results (Bortz and Doering, 2002). An online survey was conducted as this research instrument allows reaching a relatively high number of people using cancer-related online communities and therefore allows reaching the goal of this study to explore relationships that were established online.

Important design parameters of the online survey undertaken are summarized in Table 1. For more detailed information please refer to (Schweizer, Leimeister and Krcmar, 2004).

Research method	Online-survey
Period	30th March 2004 – 22nd May 2004
Universe	No exact number measurable; in theory all cancer patients that use German-speaking online-offers aligned to cancer-related topics
Sample type	Ad-hoc sample
Approach to contact potential participants	Text with information and link to the survey; posted in 28 German-speaking online-offers aligned to cancer-related topics
Analysable data sets	301

Table 1: Summary of design parameters

The online survey itself contained six blocks of questions relevant to this study: General internet usage behaviour, usage behaviour of cancer-related online offerings, virtual relationships and their social support, perceived advantaged and disadvantages of CMC, motives of cancer-related internet usage, socio-demographic and cancer-related characteristics. The questions within these different blocks were conducted either from previous research or from a qualitative pre-study within which expert interviews were conducted.

To publish the questionnaire it was written to the managers of all cancer-related online interaction offers found by simulating the behaviour of cancer patients looking for such offers using internet search engines (for the exact process see Daum and Krcmar, 2002). The managers of these interaction offers were asked to publish the link to the online questionnaire. Of 60 offers written to the managers of 28 offers agreed to publish the questionnaire. Altogether 315 people took part in the survey. 301 data sets could be used for the analysis after removing test data sets and data sets filled in by relatives of cancer patients. In these 301 data sets all six blocks of questions were answered as the questionnaire was only saved after being completed.

EMPIRICAL RESULTS

Characteristics of the Survey Participants

Of the 301 cancer patients participating in this survey 204 are female and 97 are male. The age of the respondents varies strongly with the age group of 30-59 years represented the most (n=229). Breast cancer (n=87) was the most common type of cancer the respondents suffered from, followed by haemic neoplasm (n=50). Focusing on the internet usage behaviour of the participants, it is noteworthy that the usage frequency of the internet in general and of internet services with regard to cancer in specific is relatively high. For example, the major part of the respondents uses the internet on a daily base (n=233); in average the participants spend 14 hours a week online.

Results: Virtual relationships of Cancer Patients (RQ1&2)

The first two research questions that were addressed in this study are whether cancer patients establish social bonds through online communities at all and if they do how these relationships are cultivated. The result shows that virtual relationships established to exchange about cancer are common among cancer patients using online communities: Of the respondents 141 persons (46.8%) describe at least one virtual relationship, 60 participants (19.9%) describe a second virtual relationship and 22 (7.3%) describe a third one. These virtual relationships are described as well-developed and close whereby questions measuring interdependence, depth of relationship and mutual commitment developed by Parks and Floyd were used to measure the quality of relationship (Parks and Floyd, 1996). The information exchange between the cancer patient and his / her virtual relationship takes place on a weekly (47%) or a monthly basis (29%); 72% of the participants exchange non-cancer-related information in addition to information about the disease.

Answering RQ2 Table 2 shows that it is quite common that relationships established via online channels are transferred to the real world and cultivated through both virtual and non-virtual means of communication.

Means of communication	% of N=232 (all virtual relationships)
Face-to-face meeting	38.6
Via telephone	37.3
Via e-mail	82.1
Via letter	9.9
Online forum	82.1
Via chat	29.6
Other	4.0

Table 2: Usage of different interaction channels

Results: Determinants of Virtual Relationships (RQ3-RQ6)

The results to RQ1 show that many, but by far not all cancer patients using online communities develop virtual relationships. Therefore, in the next step influencing factors on whether or not the respondents establish virtual relationships are analyzed.

Socio-Demographical Characteristics and Type of Cancer (RQ3)

To measure the effect of the different socio-demographical characteristics such as gender, age, marital status, education and current occupation on whether the respondents establish virtual relationships or not, chi-square tests were applied. None of the characteristics showed any significant result ($p > .05$). Furthermore, the assumption that persons with uncommon types of cancer rather build up virtual relationships than persons with common types of cancer could not be proven either (chi-square test; $p = .982$).

Internet Usage Behavior (RQ4)

First it was tested whether characteristics of generic internet usage influence the existence of virtual relationships of cancer patients. Chi-square tests showed no significant influence of any of these characteristics ($p > .05$). But, when the influence of the internet usage behaviour with regard to cancer-related topics on the development of virtual relationships was tested, chi-square tests showed significant results: The length of time, since when the internet is used with regard to cancer-related topics, has a positive influence on the existence of virtual relationships. Persons using the internet for cancer-related inquiries for a period of only 0-6 months lack virtual relationships. Cancer patients who have been using the internet for more than two years for cancer-related topics are more likely than average to cultivate virtual relationships ($p = .009$). Also, when cross tabulating frequency and duration of internet usage with regard to cancer-related topics against the existence of virtual relationships the results show that patients who use the internet daily with regard to cancer-related topics and patients who use the internet more than seven hours per week for cancer-related topics are more likely to have virtual relationships than expected values propose. All other groups are less likely than expected values propose. Furthermore, patients actively using online interaction services (posters) are more likely to have virtual relationships than patients only passively using them (lurkers) (chi-square test; $p < .001$).

Motives of Internet Usage (RQ5)

The three motives of internet usage “interpersonal utility” “pass time” and “information seeking” were measured with 12 different questions. Principal-component analysis with varimax rotation was used to measure whether this 12 questions loaded on the expected three motives (eigenvalue = 1.0). Factors were retained on the basis of the “scree” plot and on the requirement that eigenvalue be greater than 1.0. An item was retained if it had loadings exceeding .50 on a factor and no cross loadings exceeding .40. Of the original 12 questions 11 were retained. They loaded as expected on the three motives defined previously by Papacharissi und Rubin. Looking at the three motives of internet usage, Table 3 shows that “information seeking” is the most important motive for using cancer-related internet services, followed by “interpersonal utility”. The respondents agreed strongly to both motives whereas the disagreed to use the internet with regard to cancer-related topic to “pass time”.

Motives of internet usage	Mean	Variance	Correlation (r)	Significance (p)
Interpersonal Utility	2.53	0.58	.332	< .001
Information seeking	1.65	0.44	.003	.964
Pass time	4.13	0.78	-.036	.547

Annotation (5-point scale from „Totally agree“ = 1 till „Do not agree at all“ = 5)

Table 3: Motives of internet usage

To measure the influence of these three motives on the existence of virtual relationships a correlation analysis was conducted using Spearman’s rank correlation coefficient. The correlation analysis indicated a modest positive linear relationship between “interpersonal utility” and the dichotomous variable existence of virtual relationships ($r = .332$, $p < .001$). For the two other motives no significant correlation could be found ($r = .003$ / $r = -.036$; $p = .964$ / $p = .547$). Therefore, it can be concluded that neither “information seeking” nor “pass time” have an influence on the development of virtual relationships whereas, quite logically, “interpersonal utility” has.

Perceived Advantages and Disadvantages of Computer-Mediated Communication (RQ6)

All measured advantages and disadvantages are perceived as such by the participants of the survey. A correlation analysis using Spearman’s rank correlation coefficient was conducted to measure whether perceived advantages and disadvantages influence the existence of virtual relationships. All results of this analysis are shown in Table 4. Significant correlations are marked bold.

Perceived Advantages and Disadvantages of CMC	Correlation (r)	Significance (p)
Advantages		
The internet allows me to find other people who made similar experiences	.223	.000
I can use the internet independently from time of day	.145	.013
The internet allows me to contact many different persons with a lot of different experiences and information with regard to cancer	.157	.007
I can use internet offerings independently from a specific place	.084	.152
I can remain anonymous	.057	.330
There is no prejudice through others	.001	.990
Answers are more profound than in most face-to-face conversations since people have more time to formulate their answers.	.081	.165
On the Internet it is easier for me to be open	.072	.219
Disadvantage		
It takes longer to get answers than in a face-to-face conversations	-.044	.456
Sometimes people make comments on the internet that are factually wrong.	-.004	.944
Sometimes people make comments on the internet that are misleading.	-.046	.438
My conversation partners are not always accessible since they are not online all the time.	-.046	.435
On the Internet there are no possibilities to touch your conversation partner (e.g. hugging, etc).	.000	.994
Lack of gestures and facial expression can lead to misunderstandings	-.131	.025
There is no possibility to hear your conversation partner's voice.	-.059	.314
The internet makes it difficult to establish personal relationships	-.318	.000
Other people are making remarks that don't have anything to do with the subject	-.062	.296
Other people make hostile remarks	-.019	.746

Table 3: Perceived Advantages and Disadvantages of CMC

Results: Social support through Virtual Social Relationships (RQ7)

Social support plays a major role in positively influencing the well-being of cancer patients. Social relationships of cancer patients have 'the task' to provide this social support. To measure what kind of social support virtual relationships of a cancer patient provide the respondents were asked 'How does this person support you with regard to your disease?'

Overall, 'to listen' was the most frequently given answer. Moreover multiple participants emphasised how important it is that their conversation partner made similar experiences. One respondent stated: *'The person understands me, because the person was also affected by the disease. Somebody who never suffered from cancer does not understand me this way'* Also, types of emotional support, like 'understanding my situation', and 'encouragement' were often mentioned. Furthermore, informational support by their virtual relationships was frequently listed by the respondents.

Although, as the answers to RQ2 show, many of the virtual relationships have been transferred to the real world, practical types of support like visiting or doing errands were only mentioned twice. This shows clearly that, although practical types of support would be possible, informational and emotional types of support clearly dominate virtual relationships.

CONCLUSION

The aim of this study was to examine whether online communities meet their theoretical potential to provide an environment where social relationships can be established that help cancer patients in coping with their situation. Looking at the results of this research, it can be said that, generally, online communities meet these potential and provide a place where cancer patients can interact with other people, exchange information and establish social relationships that supplement their social network. Whether cancer patients using online communities seize this chance depends from different factors. Whereas the process of developing virtual social relationships is not influenced by socio-demographical characteristics of patients, it is influenced by their internet usage behaviour, their motives of internet usage and their perception of advantages and disadvantages of online communities.

Concluding, it can be said that virtual relationships among cancer patients who use internet offers are relatively widespread. These relationships play a central role in meeting social needs of patients. Particularly other cancer patients are very important for assuring informational and emotional support and therefore, in helping cancer patients to cope with their situation.

Figure 4 summarises the findings of this study as to determinants on the development of virtual relationships and the effects of such virtual relationships for cancer patients in Germany.

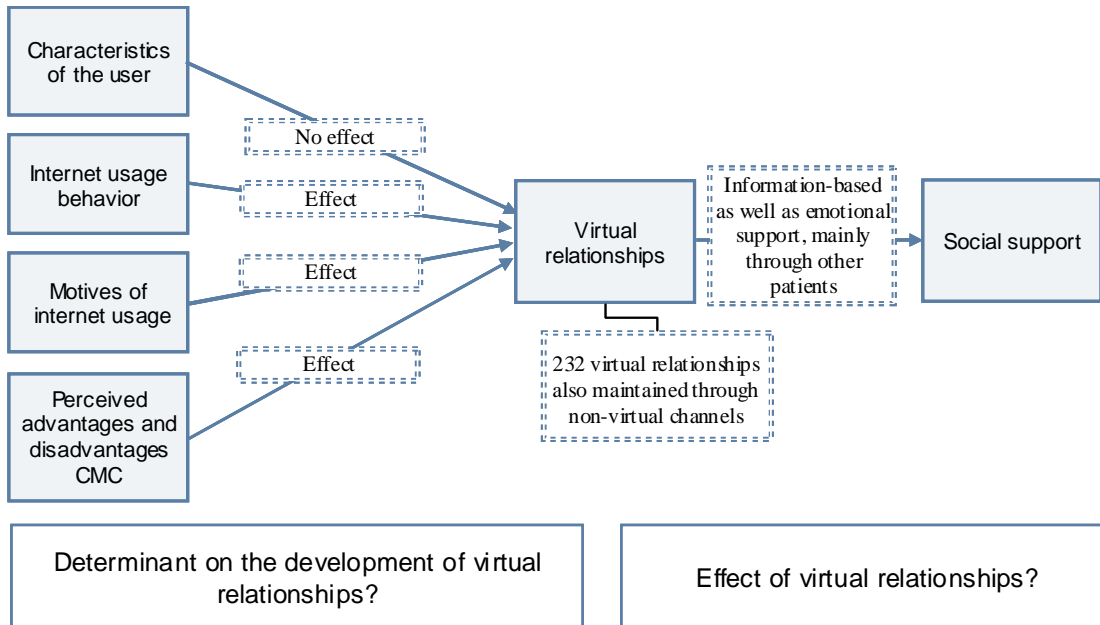


Figure 4. Results of the research survey

Recommendations

Virtual communities and virtual relationships can improve the situation of cancer patients by offering them a place to establish social relationships that help them to cope with their situation. But these virtual relationships have boundaries. Like the perceived disadvantages of CMC show (wrong and misleading information), information from the internet generally has to be checked. Also, although virtual relationships offer informational and emotional types of support, they do not seem to offer practical types of support. Therefore, virtual relationships can play an important role in complementing real-life social relationships, but they can never replace them. Given the diversity of communities in the internet and based on the results of this study, especially how respondents in this study judged advantages and disadvantages of CMC, several recommendations for patients and operators of virtual communities were deduced (see Table 4). For more information see (Schweizer et al., 2004).

Recommendations for Cancer Patients
Review information obtained online.
Consult experts to find out which internet sources are trustworthy
Be aware of your own responsibility towards other (e.g. when providing them with information).
Recommendations for Operators
Support quality assurance for health-related content.
Moderate news boards to assure quality of postings.
Require user registration to prevent misleading and hostile remarks.
Provide instructions to community members how they should handle information obtained online.
Implement synchronous interaction services to decrease the perceived disadvantage of delayed feedback.
Introduce personal pages and web-conferences to reduce the problem of missing non-verbal cues.

Table 4. Overview of deduced recommendations for patients and operators

Limitations of the Study

As a result of the research design the study has to deal with some limitation: Due to the adhoc sampling method the obtained results can not necessarily be regarded as representative. Secondly, the underlying research design only researched those cancer patients using online communities which are per se a lot more likely to establish virtual relationships than other cancer patients. Furthermore, the study only tested cross effects of variables to a limited extent, whereas the collected data seems to reveal many effects that need to be analysed in more detail. Future research should also focus on potential intermediating variables. Overall, once the social mechanisms taking place in online communities are better understood, the systematic redesign of online communities according to the needs of their users should be in the foreground.

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