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Peer-Support via the Internet: What kind of support is

sought by individuals with chronic conditions online.

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Abstract

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people with chronic illnesses is the internet as a medium where they can gather, share and

exchange information and support each other. However, little is known about the kind of

information shared and topics discussed online. Using the example of people living with

HIV/AIDS, this paper examines the kind of information shared and discusses the relevance of

understanding the online information exchange for the medical community.

Keywords: HIV, Internet, Information, Support

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Abstract

People with chronic illnesses are likely to show a higher involvement in decision making about their treatment options then people with acute illnesses. Of particular interest to many people with chronic illnesses is the internet as a medium where they can gather, share and exchange information and support each other. However, little is known about the kind of information shared and topics discussed online. Using the example of people living with HIV/AIDS, this paper examines the kind of information shared and discusses the relevance of understanding the online information exchange for the medical community.

Introduction

People with chronic illnesses are of particular interest to medical marketers, both because they represent a potential long-term customer base and because they are normally better informed about their conditions than people with acute illnesses ⁽¹⁾. Various studies have shown the importance of social support to people with chronic illnesses. Recent studies have highlighted the role of the Internet in coping with chronic illnesses in general has been highlighted in a number of studies ^(e.g. 2, 3). However, little is actually known about the way in which people with a chronic illness make use of the internet, and what kind of support and information are being sought and exchanged, especially in terms of discussions about treatment choices. Yet, an understanding of this may well be crucial from a medical marketing perspective in order to better understand the end-customer and efficiently respond to their needs for support and

information, particularly when considering that patients with chronic illnesses are likely to be highly involved in the treatment decision making process.

This paper examines the use of social support of people with chronic illnesses using the example of people living with HIV/AIDS.

Despite the progress in the fight against HIV and AIDS since HIV's emergence in the early 1980s, and transformation of HIV-infection from a deadly to a generally treatable, although not curable, disease. Previous research has shown that many people living with HIV/AIDS face a multitude of "unmet social needs" (4). Patients with this condition often feel isolated, socially stigmatised as well as being often confronted with a multitude of questions, for example about HIV and AIDS related conditions, access to support services and more general questions of living with HIV/ADIS. Of special importance to the medical marketer is that patients also often feel uninformed about treatment choices, treatment options and advances, and research related to their condition (5).

The Internet and HIV/AIDS

In recent years the rising popularity and usage of the Internet has lead to a number of researchers looking at the role the Internet can play regarding the HIV/AIDS epidemic.

Generally, three areas of interest have emerged:

- the Internet as a tool for HIV/AIDS prevention
- the Internet as a tool for sampling in HIV/AIDS research and
- use of the Internet to support care for people living with HIV/AIDS

The first two of these fall outside the scope of this paper, however, the Internet being used by HIV-positive individuals as a resource for accessing both medical information and social support is of particular importance for the medical community.

For people with HIV/AIDS, information on treatment and knowledge about the condition has been shown to be essential in order to achieve an active participation of patients in their health care, which in turn is essential for the health in people living with HIV/AIDS ⁽¹⁾.

In a survey of 174 HIV-positive men and 84 women found that those who accessed the Internet regularly to update their knowledge about HIV showed tangible benefits of their increased knowledge: They were less likely to have a detectable viral load, were more compliant with their medication, had a greater knowledge about their illness and demonstrated a greater knowledge of treatment options. ⁽⁶⁾

Apart from being merely a tool for providing information, the role of the Internet as a tool for support and "coping" with a positive HIV-diagnosis⁽⁷⁾ has been highlighted by researchers. In an exploratory study, based on interviews with 10 people living with HIV/AIDS (6 men and 4 women) and asking them about why and how they used the Internet as a tool for coping with their condition. The reasons given for use of the Internet could be classified into three categories: Firstly, Internet use promoted a feeling of empowerment by being more knowledgeable about HIV, secondly, it augments the social support of the individual and, thirdly, the Internet is seen as a tool for helping others.

Support needs and information seeking for people living with HIV/AIDS

People living with HIV/AIDS confront a variety of both medical as well as social needs. Not surprisingly therefore, social support has been a fundamental pillar of the HIV/AIDS provision, and most of the Aids Service Organisations (ASOs) devote a large amount of their budget to social support, such as peer support groups, meetings and so on. Despite the

available support, a large number of people living with HIV/AIDS have unmet social needs (4).

The role of social support has been highlighted ⁽⁸⁾ by comparing the psycho-social impact of a positive HIV-diagnosis in people who attended support groups, with the impact on those who did not attend support groups. People living with HIV/AIDS who attended support groups showed significantly less emotional distress, and that having access to social support is likely to benefit the individual living with HIV/ADIS substantially. A variety of other studies have shown similar positive impacts of social support⁽⁹⁾. An other study ⁽¹⁰⁾ pointed out that social support, especially access to information and an active participation of the patient in the choice of treatment, has a substantial impact on the clinical success of Highly Active Anti-Retroviral Therapy (HAART).

More generally, social support can be classified as falling into one of three distinct categories⁽⁸⁾:

- emotional support
- instrumental support or
- informational support

Emotional support is usually characterised by offering encouragement or comfort, giving a sense of belonging and a sense personal worth to the individual.

Secondly, *instrumental support* on the other hand offers practical support with everyday life, for example, by giving tips on how to access support services, or by giving practical help in a given situation.

Finally, *informational support* increases knowledge in general. It can therefore help to make people feel more empowered when dealing with a given situation, without necessarily being instrumental at the time the information is received.

Despite the positive impact of social support, many people living with HIV/AIDS do not have access to social support: This may be because individuals choose not to seek such support, e.g. because they fear discrimination or stigmatisation, or because individuals may employ an avoidant coping strategy (i.e. refuse to believe that they are infected, refuse to believe the link between HIV and AIDS, etc.), or thirdly, support may simply not be available in the area where the individual lives or may not be suitably accessible (e.g. in a rural or remote setting). Finally, given constraints on spending for social support, traditional social support both from peers as well as professional support is increasingly under risk (11).

Support via the Internet

Given the financial pressures on social support and related cut backs in services provided, support via the Internet, especially peer support, may become increasingly important. In fact, "cyber support groups", such as Internet forums, email groups and Internet chats offers some distinct benefits when compared to traditional support groups:

Firstly, online support groups are comparatively cheap to run as they do not require physical rooms for meetings, and thus do not require rent or other expenditure to make these facilities available. Secondly, online support is available on-demand at any time of the day or night. Thus it offers a unique advantage over the traditional support stetting in that a people living with HIV/AIDS can access support when support is needed, rather than when a support group is scheduled by the local ASO. Thirdly, because of the relative greater "reach" of online support, online groups can enable a wide variety of different people to communicate with each other, thus for example enabling people to seek out peers which because of their limited numbers or great geographic dispersion would be relatively hard to find in a traditional setting (e.g. the "Positive network for parents with HIV/AIDS"). Finally, online support groups offer

relative anonymity, thus lowering the possibility of being identified and potentially facing discrimination.

Despite the positive role social support via the Internet could potentially play for people living with HIV/AIDS relatively little is known about what type of support is being sought online, or what role such a support could play, especially in terms of treatment choices. Although an exploratory study into the positive impact the Internet support has been conducted ⁽⁷⁾, little follow up data is available. This study looks at what type of support and information is being sought and given by people living with HIV/AIDS online, and what kind of topics play an important role in one online "community". This in turn, also highlights the topics of particular concern for users of online support groups, and thus may lead to a better understanding what information is being exchanged.

Methodology

In order to find out what type of support is being sought by people living with HIV/AIDS online the present study content analysed the topics posted in an Internet support forum for people living with HIV/AIDS.

The forum is a German language forum for people living with HIV/AIDS, tied-in with a general information site about HIV/AIDS, focusing mostly on providing treatment and research updates, as well as some general information and support for newly diagnosed individuals (such as introductory information on drugs and drugs classes, HIV infection, and other more general information). The forum was chosen because the website statistics were readily accessible to the researcher, because of the size (largest and most active forum in German) and because the forum has a large amount of contributions both from newly diagnosed users as well as those who have lived with HIV/AIDS for a long time.

The forum itself is a typical discussion forum as can be found frequently on the internet: It is subdivided into a number of "sub-forums", such as living with HIV, questions regarding the treatment of HIV/AIDS, questions about side effects, nutritional questions, studies and research related to HIV as well as a section dealing with fear of getting HIV. The discussions (or messages) in each sub-forum are again grouped by topics (sometimes called threads). All users can add new topics for discussion with other users; or they can respond to questions posed by other users.

Although the largest section of the website is the "fear of HIV"-sub-forum (with 405 topics and 2794 messages posted during the year of analysis) the topics in this section are usually related to testing for HIV infection and the risk of contracting HIV, and not with dealing with HIV infection. Because the focus of this study are people living with HIV/AIDS, topics posted in the section "Fear of HIV" were excluded from the analysis.

In total, 433 topics were included in the analysis (representing a total of approximately 2440 individual messages). This represents the total of all topics posted in the forum, excluding the "fear of HIV"-section, within one year.

For each topic, the original post (i.e. the question asked or information provided) was content analysed and coded according to the framework identified in the literature ⁽⁸⁾, i.e. as being either a topic providing informational support, or a topic asking for emotional or instrumental support. Each topic was further grouped with similar subjects, in order to provide a qualitative analysis of what kind of questions were being asked (e.g. related to treatment, side effects, personal problems, and so on). 100 random topics were then recoded by a second coder, in order to establish intercoder reliability. Cohen's kappa was calculated as 0.96 for the types of support and 0.83 for the topics discussed, which is deemed to be acceptable for this type of study ⁽¹²⁾.

However, not every reader of internet forums necessarily posts in the forum or replies to topics: Thus for each topic the number of views (sometimes also called "hits" or "page views") and the number of replies posted are also given. This enables the researcher to distinguish how many people have looked at a topic (views) and how many people have responded. I.e. topics with a high number of views indicate that these topics were read by a large amount of people and are therefore likely to be of interest although they may not necessarily elicit replies from other forum participants. Similarly, topics which received a large number of replies are likely to be emotionally more involving, or even contentious, though may not necessarily be read by a large amount of people (as indicated by the views).

Results

As can be seen from table 1, there are significant differences in the types of social support being sought online ($\chi^2 = 96.82$, p < 0.01).

Table 1: Types of topics

	Emotional		Informational		Instrumental		Total	
No of Topics:	156 (36.0%)		206 (47.6%)		71 (16.4%)		433 (100%)	
	Views	/iews Replies Vi		Replies	Views	Replies	Views	Replies
Average No:	464.55	7.02	310.94	4.65	387.61	5.46	387.61	5.46
Minimum	21	0	12	0	102	0	102	0
Maximum	2099	93	1993	55	1438	17	1438	17

The largest amount of topics related to informational support (47.6%), with relatively fewer topics asking for emotional support (36%) or instrumental support (16.4%).

However, informational support had the largest amount of topics posted, topics with informational character also commanded the smallest amount of views (or "hits" per topic)

and the smallest amount of replies to each message opening the topic/thread. The latter may be less surprising because informational topics would not generally ask about the opinion of peers or what to do, and thus would elicit fewer replies from other users. Yet, the relative lack of views seems to suggest that there is also a relative lack of interest in informational topics.

Despite being only second in terms of number of posts, in terms of views and replies to topics, however, emotional support topics significantly outscored the other two support types.

In order to find out more about the kind of subjects discussed, the topics were also coded by subject in order to see what issues were important for people living with HIV/AIDS using the forum online (given as "topic subject" in the tables that follow).

Emotional Support

Table II gives an overview of the subjects being discussed when the topic asked for emotional support, i.e. all the posts were asking other forum members to provide emotional support in some form, whether this is positive support because of good news or asking about what to do in a certain situation.

Table II: Emotional Support

			Views of each topic			Replies to each topic		
Topic subject:	N	%	Average	Min	Max	Average	Min	Max
Medical Support	47	30.13	448.32	69	1100	6.87	0	27
Relationships	28	17.95	477.93	21	2099	7.07	0	27
Help (personal)	26	16.67	525.62	114	1052	7.12	0	25
Other	24	15.38	423.63	90	1211	5.75	0	25
Discrimination related	12	7.69	512.17	146	1596	13.17	1	93

Most topics posted related to questions about medical support (30.13%), i.e. a lot of the topics posted were topics which shared medical results, this included often naming of the current

medication regimen the person was on. For example, in a number of topics, people shared their treatment successes by posting their latest laboratory results together with a brief medical history. These were then often "cheered" by other forum members.

The second largest subject group asking for emotional support was topics directly related to relationships and love (17.95%), especially in this case disclosure of HIV status in relationships and how to handle sero-discordant relationships were fairly frequently discussed.

Another interesting area was a subject area where people shared more general stories about their life with their peers online, especially as this area recorded the highest number of average views of all the topics (i.e. not only looking at emotional support topics). Equally the average reply value for topics in this subject area was the highest, together with topics asking for support regarding discrimination.

Discrimination-related topics in turn were interesting as this subject area was only relatively infrequently subject of the discussions (7.69% of the emotional support topics). Yet at the same time this area showed the highest average number of replies (13.17), one topic with by far the highest number of replies overall (93) yet the average views for topics in this area were not the highest. This result is interesting, because on the one side it seems to suggest that discrimination related topics are at least not the largest issue faced by people living with HIV/AIDS seeking support on line. This may be because of two reasons: Firstly, the 'general public' might have become more knowledgeable (or tolerant) of HIV infection and therefore discrimination may be less frequently encountered, or secondly, because of treatment advances HIV infection may no longer be a fairly easily identifiable illness in everyday life (e.g. by the reduction of openly visible opportunistic infections such as Kaposi Sarcoma) and by a general reduction in morbidity, and therefore giving a reduced need to disclose HIV status in everyday life. The answers posted suggest that although few people asked questions

related to discrimination online, most people had developed a certain *modus operandi* of how and where/when they would disclose, thus suggesting that discrimination may well be more of an issue faced in everyday life than the numbers would seem to suggest. This would also suggest that the low incidence of discrimination related topics is likely to be a function of a decreased need to disclose, rather than the effect of a more tolerant and educated society.

Informational Support

Within the group of topics which fall under the informational support category, a fairly large number of topics are discussed. The messages in this category often have a merely information sharing character, and therefore most messages do not ask for feedback or support from other forum members, which explains the often very low number of replies (e.g. a average reply rate of 3.04 for topics directly related to research). Although this is the largest category (47.6% of all topics), fewer people look at the topics in this category (average views of 310.94/topic) than at topics which ask for emotional (average 464.55 views) or instrumental support (average 387.61 views). This seems to suggest an apparent 'lack' of interest in these topics, which may well be explained by increased treatment optimism in the forum participants, which may make research news less interesting to read than emotional support questions.

Research news related topics and information seeking about treatments (i.e. topics directly related to HAART medication) and general information (which encompasses a wide variety of topics ranging from television programmes and films which deal with HIV/AIDS or news about seminars and other events being offered by local AIDS service organisations) dominate this category in terms of numbers of topics posted.

Table III: Informational Support

1		
	Views of each topic	Replies to each topic

Topic subject:	N	%	Average	Min	Max	Average	Min	Max
Research	49	23.79	254.16	63	887	3.04	0	23
Treatment (HAART)	35	16.99	314.31	68	781	5.20	0	26
General Information	34	16.50	238.76	82	538	3.12	0	18
Wellness/Nutrition	17	8.25	410.29	44	1139	6.00	0	16
HIV (general)	17	8.25	366.18	12	986	5.88	0	20
Complementary Med.	13	6.31	530.31	111	1993	9.62	1	55
Ois/Symptoms	11	5.34	319.64	42	575	4.36	0	8
Side Effects	10	4.86	190.40	72	312	2.80	0	8
Treatment (not HAART)	8	3.88	471.75	96	1083	9.13	0	25
Political/Activism	7	3.40	186.29	83	310	2.00	0	9
Social Services	5	2.43	277.80	135	891	4.8	0	15

It is also noteworthy that information about complementary medicine, although overall only the subject in comparatively few topics (6.31%), does show to be a somewhat controversial topic: Topics in this category have the highest number of average replies (average 9.62) as well as on average more views than other topics (average 530.31), more reminiscent of topics in the emotional support category. Interestingly the somewhat related category of wellness and nutrition, although slightly more numerous in number of topics, does not seem to cause any controversy with the forum members, and the average number of replies is considerably lower (average 6.0) than for topics related to complementary medicine (average 9.62).

Another interesting point is that political and activism related topics are the topics with the lowest views by fellow forum members, less than 50% of the average views for all topics. This suggests that the early days of the AIDS epidemic with often a large scale political and social activism seem to have passed, or at least are not reflected in the behaviour of the online

community.

Instrumental Support

The instrumental support category, overall the category with the fewest posts, is dominated by questions about how to deal with side effects of HIV treatment in every day life (33.80%). Fewer topics look at access to services related to HIV, such as access to medical services (such as help in finding a treatment specialist), access to social services (such as help with applying for benefits) and access to support services (such as access to local support groups).

Table IV: Instrumental Support

			Views of each topic			Replies to each topic		
Topic subject:	N	%	Average	Min	Max	Average	Min	Max
Side effects	24	33.80	378.96	102	1055	5.21	0	15
Acc. Medical	12	16.90	403.83	148	1438	6.17	1	17
Symptoms	10	14.08	342.10	206	527	4.50	0	11
Access Social-Services	9	12.68	483.89	159	996	5.11	0	14
Drugs-specific	6	8.45	392.33	248	583	8.00	3	17
Access SupServices	5	7.04	380.40	170	676	6.00	1	11
Other	5	7.04	309.40	233	392	4.00	2	6

There are also comparatively very few topics related to dealing with direct symptoms of HIV infection in everyday life, again possibly a sign of the relative success of the medical treatment (and treatment for symptoms) available, as discussed previously.

Discussion

As expected, the sharing of information and seeking of support online often involved direct or indirect discussions about the treatment the user was having or likely to have. Primarily the main focus of the users of the Internet forum seems to be to provide (and ask for) emotional

support, especially the sharing of medical (often success) stories, however, this often involved naming of brand names and comparing results of the medication with other users.

In fact a number of users have a brief summary of their current medication and laboratory results as a signature (e.g. "Poz 2003, Combivir/Sustiva since 2004, VL <50, CD4 439", meaning that the user tested positive in 2003 and is currently on a combination of Combivir® and Sustiva® with an undetectable viral load and a CD4 count of 439), i.e. the user "branded" him/herself and all of their messages with this information. Thus, each post of the user would show this information similar to an email signature, irrelevant of whether or not this information was asked for or relevant to the discussion. This sharing of information about treatment successes and treatment details is of course very interesting from a marketing perspective, as most mentioning of the medication either by brand name or generic name is potentially an endorsement of the medication to other end-users, especially those that are seeking information about a suitable combination therapy for them (e.g. users who have to switch medication, or newly diagnosed patients not yet on therapy). Each topic was viewed on average by 450 users: i.e. a substantial group of people who read about the medication experiences.

Equally, questions directly related to HAART-medication was the second most important category of topics asked in the information support category, with 17%, 314 views per topic and around 4 replies in each topic. These topics are mostly dominated by the discussion of particular experiences with any given HAART-related drug, thus the direct sharing of experiences with the various products available.

However, apart from these two categories, medication was also discussed frequently in terms of the side effects (33.8% of the topics posted in the instrumental support section, with an average of 378 views each) – again often by naming names of medication suspected of

causing particular side effects, and asking for help with the side effects or alternative options where available.

The widespread discussion of medication among end users, including suggestions about treatment alternative, support in finding the right treatment, and treatment successes must be of major interest to medical marketers. Although little is known about how and if patients who ask (or read about) advice in the forum will discuss this advice with their care providers, it is likely that some people will – and in turn that advice received from fellow forum members may well be a significant factor in making treatment decisions.

Overall, the forum topics seems to reflect the positive impact which modern treatment has on the quality of life for people living with HIV/AIDS, and the sharing of medical success stories (rising CD4 counts and undetectable viral loads while on HAART) seems to take centre stage in the Internet forum examined. At the same time more traditional fields of HIV-support groups seem to have diminished greatly, or are at least only a fairly small amount of the topics discussed online: Neither discrimination topics nor political activism seems to play an important role in the online community: politically motivated and activist topics seemed to reduced the amount of views dramatically, suggesting that at least the online community is (no longer) interested in these topics. However in the case of discrimination, it appears that the reduced need of disclosure also results in a relative less importance of the discrimination topic area.

At the same time, topics related to complementary therapy seem to ensure a certain controversy, as well as generating a relatively high of interest in terms of viewers looking at those topics. This may not be surprising, given that a US-based study ⁽¹³⁾ reported that 53% of people living with HIV/AIDS had used complementary medicine, a proportion much larger than in the general population. Experience with complementary therapy may explain the relatively large amount of views/replies for subjects related to it, similarly prior experience of

users may explain why medical stories (especially success stories of HAART treatment) featured heavily, while discussion about discrimination issues were quite intense when raised, but not prominent overall. Concerning discrimination, the relatively few topics are likely to be a function of decreased morbidity and therefore decreased need to disclose, rather than a more educated general public. Thus, in general the research suggests that topics with generally high "experience" value of the participants generate more views and replies than topics in which participants have less experience in. This in turn also suggests that although the number of topics are interesting, the replies/views may offer a better guide to how widespread the problems/questions are in this type of research.

As this research is exploratory in its nature it has a number of significant limitations, while at the same time opening avenues for further research. Firstly, the research was carried out by content analysis of a forum in German, thus the majority of the participants in the forum are likely to be from German-speaking countries. Therefore the results may be different in another setting, i.e. when applied to a different country. In fact, it would be interesting to see how these results compare to other forums in other countries, and what influence factors such as culture or healthcare and social systems in different countries have on the types of topics being discussed. Secondly, the research only looked at the topics posted, with no information about the demographics of the forum participants, their medical history or how active certain participants are in comparison with other participants. Thus, further analysis may be useful in two key areas: demographics of forum participants and further analysis about the people opening topics. Equally, there is a "digital divide" (6) in terms of people living with HIV/AIDS who access the Internet, and therefore the people participating in the forum may not represent the average demographic distribution of people living with HIV/AIDS in Germany. Alternatively, it is also conceivable that the majority of people who do use the Internet in order to seek support do actually face some form of difficulty or support need themselves, i.e.

they may represent those people who are seeking support more than a potential majority who cope without (additional) support needs. Finally, little is known about if and how the forum participants access other support services, or what role the Internet forum plays in the overall support sought. For example, it may be that some participants make exclusive use of the forum; others may use a variety of support services, i.e. they may combine online as well as off-line support.

Related to the previous point, it would be interesting to know what influence other forum participants have on the decision making process of forum participants. Previous studies, both in general purchase decision making⁽¹⁴⁾ as well as related to the perception of health services (15), have pointed out that the internet information, and especially peer-experiences, play an important role in decision making. Thus it seems logical that information from other users may influence treatment decisions or discussions with care providers of forum participants. Such an effect seems very likely, though the current study did not address this specific issue. In conclusion, the Internet is clearly providing a platform for the active exchange of information of people with this chronic illness, and treatment related questions seem to dominate the discussion in this example, with possibly strong implications for decision making by these individuals. To further the understanding of how far the internet plays a role in decision making, it seems viable to extend this study to other conditions and to study the influence the information received via the internet may have on the actual discussions with care providers and treatment choices made. Equally, it is vital that medical marketers must understand the power such virtual discussions could potentially have, and how they can integrate this platform in their communication activities.

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