Internet use in rheumatology outpatients in 2006: gender less important

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Abstract

Objective
Exploring patients’ Internet use, their online needs and requirements, expectations and attitudes towards the Internet is mandatory to effectively provide interactive online applications and information.

Methods
Within a prospective study, 153 consecutive outpatients with rheumatoid arthritis, systemic lupus erythematosus or spondyloarthritis answered a paper-based questionnaire investigating their Internet use, interests, pattern and degree of utilization. Sociodemographic and functional disability data were collected. The data were compared with our survey of 2001 and to the normal German population.

Results
Patients were predominantly female (69.3%; n.s.). Mean age was 45.7±14.4 years (n.s.). 68.6% (+18.6%, p=0.0027) reported regular Internet use for 5.0±2.6 yrs. Internet use in 2006 is still age- and education-dependent (p<0.001, p=0.003). Differences by gender observed in 2001 no longer existed as women increased their Internet use from 2.9 to 6.1 hours/week (p=0.001, p=0.0006). Searching for health-related information remained an important topic. Interest in e-communication and interactive applications strongly increased. Independently of gender and functional disability, patients’ future online interests focussed on information on diseases, medications, health care providers and patient education. Confidence in the Internet and reliability of information were rated unchanged since 2001.

Conclusion
Gender no longer has significant impact on Internet use. The great potentials of Internet services – well accepted by patients and contributing substantially to more effective and improved disease (self-) management strategies – should encourage rheumatologists to provide interactive applications and high-quality information on Internet platforms and in routine patient care. Continuous research to explore the effects of Internet-delivered information on patients’ attitudes, expectations, behaviour and outcome is required.

Key words
Internet, world-wide web, e-communication, gender, rheumatology, patients, medical websites.
Introduction

Health care queries rank among the most frequent topics of information-seeking activities of all Internet users (1, 2). The majority of patients’ searches are for specific medical conditions, and the information patients retrieve online directly affect their decisions about their health care (1, 3, 4). Consequently, physicians should inquire about patients’ use of the Internet and might give advice about searching the Internet for patients’ needs and requirements (5, 6).

Moreover, patients’ access to health portals, use of web-based expert forums (ask-the-doctor services) and e-communication with health care providers have increased (7-10). Web-based online applications for online assessments, patient education concepts, patient management programs, and Internet-mediated intervention programs have become popular on medical websites (11-14). Due to the sensitive nature of medical data, the related security concerns, the varying Internet use in patients and the necessity of technology that is designed to meet patients’ needs, a careful development, implementation and evaluation of such applications on medical websites is crucial (15-18).

Patients’ needs and requirements for a medical website might be unrelated to the information offered. To maintain an optimized Rheumatology Internet platform with end-user oriented applications and developments on www.rheumanet.org (19), we investigated German rheumatology outpatients and report the evaluation of their Internet use, access modes, interests, pattern and degree of utilization of the Internet in 2006. We elucidated patients’ readiness and willingness to participate in chats and forums, as well as in interactive applications such as online patient education programs which might contribute to an advanced (self-) management of the inflammatory rheumatic diseases. To detect and provide recent trends, we compared these data with data investigated by our group in 2001 (20).

Patients and methods

In 2006, 172 consecutive patients with inflammatory rheumatic diseases (rheumatoid arthritis (RA), systemic Lupus erythematosus (SLE), spondyloarthritis (SpA) regularly scheduled for a visit in our Rheumatology outpatient clinic at the University Clinic Düsseldorf were asked to participate in our prospective study, which assessed patients’ Internet use, technical details of Internet access, pattern and degree of utilization as well as patients’ needs and requirements, using a paper-based questionnaire. The questionnaire relied on the questionnaire successfully used in our evaluation in 2001 when 326 patients participated in our survey on Internet use in rheumatology outpatients (20).

Patients’ self-reported functional disability was assessed by the Hannover Functional Questionnaire (FFbH) and a transformed Health Assessment Questionnaire (HAQ) index validated in rheumatology settings. FFbH Scores are given as percentages of full function (range 0 to 100) and can be transformed into HAQ values. The FFbH data analyses were done according to scoring used by the national database of the German collaborative arthritis centres: scores from 100 to 70% are considered to reflect normal functioning, between 50% and 70% scores indicate some deterioration in functioning, and scores <50% indicate extremely severe functional disabilities. In addition to paper-based FFbH questionnaires, patients entered their data directly via Tablet PC into our database, demonstrating a high correlation between paper-based and electronic assessments. Furthermore, patients’ sociodemographic data and education levels were collected on the basis of the data set of the national database used by the German collaborative arthritis centres (21). To assess the growth rates of Internet access, the changes of pattern and degree of utilization data obtained were compared to the data assessed by our group in 2001 (20).

One hundred and fifty-three outpatients (61 RA, 60 SLE, 32 SpA) agreed to participate, completed the questionnaires and entered the final analyses. Signed patients’ informed consents were obtained. Positive ethical approval had been received from the ethics committee, Heinrich-Heine-University, Düsseldorf.
Statistical evaluation was made using Statview® 5.01, SAS Institute Inc., Cary NC, 1999. All parametric and non-parametric tests have been performed two-tailed. P-values less than 0.05 were considered significant.

Results

Sociodemographic data

Patients were predominantly female (69.3%). Mean age was 45.7±14.4 years and varied between the different disease groups (RA 52.9±13.6 years, SLE 38.9±12.3 years, SpA 44.4±13.3 years; p<0.001). Patients using the Internet in 2006 were 41.8±12.6 years old (range 20-74 years). Age distribution of the patients investigated in 2006 was comparable to the patients studied in 2001 (p=0.5911). Mean disease duration in 2006 was calculated at 9.2±7.7 years (median 7.0), without significant differences between the three disease groups. Patients’ functional disability measured by the FFbH did not differ between the disease groups in 2006.

In accordance with the specifications of the data set of the national database used by the German collaborative arthritis centres, 19.0% of the patients had a high level of education. No significant difference in education level was noted between the RA and SpA group. Fewer patients with SLE had an academic degree; 25.5% of all patients were retired; 44.4% worked full time or part time.

Internet access and use

Internet was accessed most commonly via the fastest available access for private users in Germany: Digital Subscriber Line (DSL, 44.4%), and the most commonly used browser was Internet Explorer (49.3%).

With no significant differences between the three disease groups, 68.6% of the patients reported regular Internet use for a mean period of 5.0±2.6 years (median 5.0). Only the subgroup of RA patients with more self-reported functional disability reported Internet use less frequently. The period of Internet use in years did not differ in the functional disability groups. Internet use was not gender-dependent (67.9% in female vs. 70.2% in male patients, p=0.778) but significantly age- and profession/education-dependent: younger and higher educated patients used the Internet more frequently (p<0.001; p=0.003). The Internet was used more often in patients working full time (90.7%) or part time (82.6%) compared to unemployed patients (54.4%), housewives/househusbards (42.1%) and those already retired (43.6%). These data were consistent with our data from 2001. For further details see Table I and II.

Time spent online

The Internet was accessible from home by nearly all of the patients using the Internet (98.9%). 15.8% reported daily Internet use in 2006. The median of Internet use in days per week was 5 (range 0.5-7 days). On average, the Internet was accessed for one hour per day (median 1.0, range 0.5-6 hours/day). Age did not significantly correlate, but there was a tendency to more hours spent on the Internet for younger patients. No significant difference was evident between the three disease groups but a trend was notable: patients with SLE reported Internet use more frequently and for more hours (mean 6.9±8.3 hours/week) than the RA (mean 5.3±4.9 hours/week) and the SpA (mean 4.6±3.4 hours/week) group. Patients with more self-reported functional disability tended to use the Internet even longer (mean 9.4±8.5 hours/week, p=0.3542).

In 2006, significantly more patients used the Internet on a regular basis (+18.6%, p=0.0027) and spent significantly more hours on the Internet (Fig. 1; p=0.0270). While Internet use habits for men had not changed significantly, female patients had changed their behaviour extensively: in 2006 female patients used the Internet even longer than men (mean 6.1±7.0 hours/week in female vs. mean 5.4±5.1 hours/week in male patients) and twice as long as females in 2001 (mean 3.0±3.1 hours/week, p=0.0006).

Reasons for Internet use

In 2006, patients using the Internet named the following reasons for Internet use (Fig. 2) (values in parentheses reflect the comparison with the data reported in 2001): 87.6% access the Internet for general information (+4.7%, p=0.1522), 79.0% read/send e-mails (+0.7%, p=0.4797), 57.1% search for medical/health information (+1.3%, p=0.7563), 52.4% online shopping (+32.2%, p<0.0001), 42.9% online banking (+10.4%, p=0.0862), 18.1% play games (+8.3%, p=0.0496), 17.6% downloads, 16.2% access chat rooms/forums (+5.2%, p=0.2296), and 28.6% for other reasons (-21.0%; p=0.0006). The topics addressed in 2006 were similar for profession/education, gender, age, underlying disease, and patients’ self-reported functional disability.

With an increase of +1.3% the Internet use for health information retrieval was overall fairly stable in the complete patient group using the Internet.

Table I. Internet use by age

<table>
<thead>
<tr>
<th>Age in years</th>
<th>2006</th>
<th>2001</th>
</tr>
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<tbody>
<tr>
<td>&lt; 30</td>
<td>83.3%</td>
<td>62.8%</td>
</tr>
<tr>
<td>30 - 39</td>
<td>82.9%</td>
<td>71.1%</td>
</tr>
<tr>
<td>40 - 49</td>
<td>82.4%</td>
<td>63.8%</td>
</tr>
<tr>
<td>50 - 59</td>
<td>59.3%</td>
<td>38.5%</td>
</tr>
<tr>
<td>&gt; 60</td>
<td>36.4%</td>
<td>22.5%</td>
</tr>
</tbody>
</table>

Table II. Internet use by professional education.

<table>
<thead>
<tr>
<th>Professional education</th>
<th>2006</th>
<th>2001</th>
</tr>
</thead>
<tbody>
<tr>
<td>No professional education</td>
<td>41.7%</td>
<td>25.0%</td>
</tr>
<tr>
<td>Non-academic training</td>
<td>67.7%</td>
<td>52.1%</td>
</tr>
<tr>
<td>Academic training</td>
<td>93.1%</td>
<td>75.3%</td>
</tr>
</tbody>
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(\(p=0.7563\), see above), but women especially increased health queries by +3.5% in comparison to men (-1.4%). Sequencing the increase of health information retrieval with the other given topics the increase in health information retrieval ranks lowest. Compared to the data of 2001 in 2006 female patients were significantly more interested in online banking \((p<0.001)\) and games \((p=0.0234)\). While men increased their access to chats only by +1.6% female patients increased their access by +6.7%. Both men and women accessed the Internet significantly more often for online shopping (Fig. 2).

**Confidence in and reliability of information retrieved from the Internet**

Confidence in the Internet was rated as 3.2±1.3 (mean±standard deviation (SD)) on a 1 (very good) to 6 (bad) Likert scale independently from the underlying disease, self-reported functional disability, patients’ profession/education, gender and age. However, as in 2001, older patients rated the confidence in the Internet worse than younger patients. The reliability of information retrieved from the Internet was scored as 2.8±1.2 (mean±SD) on a 1 (very good) to 6 (bad) Likert scale. No significant correlations to age, gender, patients’ profession/education, the disease or self-reported functional disability were apparent. Internet users in 2006 rated confidence in the Internet and the reliability of its information significantly better than non-users. Having applied the same Likert scale as previously, patients using the Internet in 2006 rated the confidence in the Internet and the reliability of information retrieved from the Internet unchanged.

**Fig. 1.** Time (hours/week) spent online 2001-2006

**Fig. 2.** Topics searched and used online 2001-2006
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compared to 2001. Age and gender did not correlate with these ratings.

**Topics of further interest for patients**
The following topics of actual and further interest in the future Internet use were specified by all patients (change compared to 2001 in parentheses, \( p<0.01 \) if not specified): 82.7% information on their underlying diseases (+38.8%), 81.1% drug information (+45.8%), 35.0% online pharmacy, 73.1% information on hospitals, 55.4% online search for health care providers (hospitals and rheumatologists) (+12.5%, \( p=0.1078 \)), 45.1% patients chats and forums (+31.6%) and 54.6 % online patient education. The results were similar for the patients using the Internet already.

The topics of further interest were not correlated to gender in 2006 in the complete group or in the group of patients already using the Internet. The underlying disease both in the complete group and in the Internet group did not correlate with the topics. The only exception was that patients with SpA (66.7%) were significantly more interested in online patients chats than the RA (30.9%) and SLE (48.2%) groups (\( p=0.0093 \)).

In the complete group of 2006, younger patients were significantly more interested in information on the underlying disease, given medications and hospitals on the Internet than those aged over 60 years (\( p<0.001 \), \( p=0.0013 \), \( p=0.0025 \)). However, this was not statistically significant in the group of patients already using the Internet. The same phenomenon was notable for the topic ‘information on the underlying diseases’. The other topics did not correlate with age.

Though not statistically significant in the complete group, higher educated patients were more interested in information on medications (\( p=0.0525 \)), in the group of patients using the Internet, these patients had significantly more interest in drug information (\( p=0.0072 \)). None of the other topics of further interest were correlated to education.

**Discussion**
Our data show that in 2006 Internet use, time spent online, and interactive online activities have become much more popular among rheumatic patients typical of German patients with inflammatory rheumatic diseases (20).

Patients highly demand disease- and other health-related information on a rheumatology website. They are ready and willing to participate in e-communications (e-mails, chats and forums) and e-commerce, as well as in interactive applications such as online patient education programs leading to an optimized (self-) management of the inflammatory rheumatic diseases. These findings pose demanding challenges and opportunities to all health care and medical website providers, and the integration of patients into the developments is mandatory to meet their requirements and needs.

In comparison with cancer patients, a very high percentage of rheumatic patients access the Internet from home and patients follow the trend to use high speed Internet access for private users (22, 23). The more intense Internet use in our patients between 2001 and 2006 reflects the general trend in the German population, independently of gender the higher Internet access rates were found in our patients (24). The Internet has been adopted as an important information and communication medium by our chronically ill patients, overall Internet use and hours spent on the Internet are comparable to other published data (5, 16, 20, 24-27). In accordance with other surveys, our patients using the Internet were younger, higher educated, and more often employed than patients who did not use the Internet (5, 20, 22, 27-31).

Health information – one of the most frequently sought topics in the Internet – was searched by 57.1% of our Internet users. Andreassen et al. reported Internet use for health purposes by 71% of European and 49% of German Internet users with a wide range throughout Europe, and with 82% of their participants having mentioned current long-term illness or disability (1, 29).

The increase in health information retrieval in our rheumatic patients was not statistically significant; however, the increase in health information retrieval in five years was highest among female patients. This is most likely due to the fact that women – more than men – tend to prefer to access health sites, in part because of care-taking roles for themselves and all family members (29, 31-33). Sequencing the increase of health information retrieval with the increase of the other given topics, the increase in health information ranks on the last position only. This might be due to the fact that confidence in the Internet and the reliability of the information retrieved from the Internet were still ranked low by our 153 patients investigated in 2006 and did not exceed the values obtained in 2001. These data reflect serious security concerns emphasizing the need for medical websites that recognisably offer reliable, qualified and well-structured (patient) information (20). Considering the strong position of health issues in 2001 a saturation process in patients with rheumatic diseases and/or missing interactivity of the provided health information are alternative explanations. However, consistent with data retrieved by cancer patients and patients with digestive diseases, our patients with inflammatory rheumatic diseases highly demanded online information on the underlying diseases (82.7%) and medications (81.1%) as well as information on hospitals (73.1%) in the future (22, 26, 28). Our patients’ high interest in these topics supports findings from other studies in which drug websites had been reported to be visited by 37% of the patients and hospital websites had been used by 48% of the patients (5). In addition, the significant increases in these topics compared to our data of 2001 demonstrate patients’ wishes to use the Internet probably even more often for health information in the future (34). Recognizing that these types of health-related information are sought after and considering the aforementioned security concerns, one need to bear in mind again the need for extensive, high-value, reliable scientific and appropriately addressed information offered on an end-user oriented medical website (5, 20, 32, 34). Besides lists of reliable related websites providing parts of the required topics of interest, patients need website-specific and
proper guidance to find the information and to begin and maintain an intense and interactive online dialogue with the medical experts (35, 36).

E-commerce as an emerging and for patients very interesting sector is reflected by the growth of patients reporting online banking (+13.2%), online shopping activities and interest in online pharmacies. Online shopping has gained more acceptance in general and is comparable to the German population but has increased in our rheumatology patients in 2006 by +32.2% compared to our data retrieved in 2001 and compared to data reported (20, 24, 37).

Accessing online pharmacies to obtain prescriptions without leaving home is convenient and might motivate patients with functional disabilities—thereby given decreased mobility and/or psychological aspects to do other convenient home-based online shopping (38).

However, the increase in health-related e-commerce (e.g. money spent online for alimentary supplementary products or other adjuvants) might increase patients’ out-of-pocket costs (39).

Internet health applications appear to have largely positive effects on users because they tend to become more knowledgeable, feel they are better socially supported, and may have improved behavioural and clinical outcomes compared to non-users (40-42). Web-based patient management programs – though they may not be a complete substitute for face-to-face contact – and other e-health services have a great potential as they may dramatically facilitate the ability of physicians to monitor patients’ health, empower patients and improve patients’ clinical status with time efficiency (43-48).

Our patients’ high motivation for online patient education (56.4%) in the future, the increased use of emails, as well as the significantly increased access of chat rooms and forums make broad e-communication and patient management programs on a rheumatology website even more feasible. Collecting self-reported outcome data is enhanced by patients’ increasing use of the Internet, although some patients, especially those over the age of 50, may have some difficulty in running applications on the web.

Our data support previous findings that our patients use the Internet similar to patients with other chronic conditions (20, 34). Thus, rhematic diseases display no barriers to the access and use of the Internet. Given the ubiquity of the Internet, like other patients, our patients with rhematic diseases begin to demand many different kinds of health web services from health care providers and medical websites (29, 46).

Offering interactive patient education and management applications, convenient health related e-commerce applications, as well as high-value, reliable scientific, authoritative and self-explanatory information adapted to patients’ needs and requirements will ensure the acceptance of the Rheumatology Internet platform www.rheumanet.org in the future and thereby contribute to improved quality of care including a more continuous relationship between patients and providers (2, 20, 36, 41, 43, 49). However, all interventions should be continuously evaluated to explore the effects of Internet delivered information on patients’ attitudes, expectations, behaviour and outcome.

The fact that women have more interest in researching health issues on the web than men and most rhematic diseases affect preferentially women, as well as the knowledge that men are less engaged in decision making with physicians, define conditions and offer considerable opportunities in patient information services and for medical websites (36, 50).

Future studies should address the issue, whether women favour gender-specific medical website construction, design, advertisements and/or guidance.

One limitation of our study might be that the group investigated in 2001 consisted of a wider spectrum of inflammatory rhematic diseases than the patients investigated recently. We studied a limited case group of rhematic patients and therefore data can not be generalized to e.g., patients with osteoarthritis or polymyalgia rhematica. Comparisons between 2001 and 2006 are hampered by the rapid developments of the Internet. In addition, we focussed on rhematic patients from a university outpatient clinic. Though being one of the target populations for any web-based or Internet-related research, it would be interesting to know the percentage of Internet use in more rural populations and patients that do not use third level rheumatologic centres. Therefore, further investigations are needed in different settings and regions, as well as larger populations.

Conclusion

Next to patient information, Internet offers great potentials and new opportunities for e-communication, patient monitoring, disease (self-) management and clinical research. Our data support that patients in rheumatology – especially women – have significantly increased Internet activity. Therefore, interactive Internet services on a patient oriented rheumatology website and in routine clinical care will contribute substantially to effective and improved disease (self-) management strategies.

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