A Snapshot of Renal Transplant Patients Using Medical Web Browsing

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Abstract

Objectives: **This study explored the pattern of Internet use by renal transplant patients in the West of Scotland.**

Materials and Methods: **A 31-item questionnaire was used to obtain information about patient's Internet use and the relations between Internet use and sex, age, education, and health requirements.**

Results: **The study consists of 84 postrenal transplant patient surveys. Validation of the questionnaire showed an intraclass correlation coefficient 0.77 to 0.96 with 95% confidence interval (CI 0.75-0.99). The overall response rate was 65% (n=84/130). In all, 87% of the patients (n=73/84) had access to a computer and the Internet. And 94% of the patients (n=60/64) in age groups 21 to 60 years had access to the Internet with no difference in the access in various age subgroups, whereas 67% of the patients (n=12/18) in age group 61 to 70 years (*P* = .004) had Internet access. The Internet was a preferred source of health information for 70% of the patients (n=59/84) as compared to books 17% (n=14/84; *P* = .003) and magazines 12% (n=10/84; *P* = .001). Of the Internet group, 90% (n=53/59) looked up information on transplantation mostly about transplant operations (69%) and rejection (66%). Of all the patients, 85% (n=71/84) of them would like the transplant team to develop a Web site for information on transplantation and 52 (62%) would like to receive health advice by e-mail.**

Conclusions: **The majority of renal transplant patients use the Internet for information on transplantation. Almost all patients under 60 years old had access to the Internet for this purpose; suggesting a trend toward the Internet as the favored way to get information. Transplant units should develop flexible, Web-based sources of transplant-related information. This would allow rapid adaptation to changes in prevalent practice, reflecting the preferences of the patient population.**

Key words: *Renal transplant, Medical Web browsing, Transplant information, Internet transplant resources, Transplant Web sites*

Introduction

The Internet is a popular communication tool that has a role to play in patient-centered care. It allows stakeholders to readily access health information, with the potential to substantially influence relations between patients and health professionals; for example, by evolving from the traditional model of "the doctor administering advice and medications" to one of "shared decision-making."[1]The Internet has been used as a source of health information since the early 1990s and is now an increasingly popular choice.[2] Two British surveys recently have shown a gradual increase in public interest in the use of the Internet for health information.[3-5] It has been argued that a driving force behind demand for online health information is the shortage of information easily obtained from traditional channels.[6] With the duration of an average consultation still only 7 minutes in the United Kingdom (and 12 minutes in the United States), it is perhaps unsurprising that professionals may routinely fail to address the information needs of consumers.[7]

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As well as providing information, the Internet, being available at all times, also supports conferences and chat rooms and provides the opportunity for long-term ongoing support among patients and between patients and providers.[8, 9] In addition, the Internet can be used to monitor patient status, collect data, and provide tailored feedback and self-management counseling, and offers the advantages of interactivity, information tailoring, and anonymity.[10, 11] This provides the potential for opportunities for patients to become well-informed and to take an active part in their own treatment process. However, such use of the Internet also raises many issues concerning the quality of the information available and the relationship between patients and health care providers.[12, 13] The Internet has the potential to provide rapid, up-to-date communication, which patients can access at their convenience, and to enable patients to learn more about their disease and treatment options; therefore, being better educated as consumers.[14, 15] The current literature shows that by using different information sources to educate patients such as booklets, leaflets, structured teaching, and the Internet—patients experience less anxiety, were more-easily mobilized, and had a higher level of satisfaction after different types of surgery.[16, 17]

As a result of the increased number of transplants, and because transplants are now more successful, there is a constant increase in the overall number of posttransplant patients in the United Kingdom.[18] This leads to increased pressure on primary and secondary care centers and indicates a need for patients to gain support without the hospital sector. The complexity of renal transplantation, its risks and attendant ethical considerations, means that open ongoing access to information is essential for informed consent and patient understanding.

This study aimed to explore trends of the Internet use by renal transplant patients in a well-established renal transplant center. Furthermore, the outcome could be used in making strategies to develop Internet sources to support patient management in the modern era of E-technology.

Materials and Methods

A 31-item questionnaire comprising a mixture of open and closed questions was developed. It was initially tested by administering to medical and nursing staff. It was modified according to feedback and subsequently retested by a pilot study involving 10 transplant patients. An intraclass correlation coefficient was calculated to assess the validity of the questionnaire. It was used to obtain information about a patient's Internet use and the relations between Internet use and sex, age, education, and health requirements. Further questions were about the sources used for health information, type of health, and transplant information explored and patients view about transplant Web sites. The survey was conducted by distributing this questionnaire to 130 renal transplant patients by mail, and also during their inpatient stays in the hospital between August 2009 and July 2010. In cases of no reply after waiting for at least 4 weeks, a reminder was sent to the nonresponders. Information obtained by the questionnaire was converted to spreadsheets and analyzed using SPSS (SPSS: An IBM Company, version 15.0, IBM Corporation, Armonk, New York, USA). Kruskal-Wallis or t tests were used to compare different subgroups and P values $< .05$ were considered significant. The study protocol was examined by the West of Scotland Research Ethics Service and the advice was that being an invitational survey, it did not need a formal ethical review under the terms of the Governance Arrangements for Research Ethics Committee (REC) in the United Kingdom. The protocol confirmed to the ethical guidelines of the 1975 Helsinki Declaration.

Results

Validation of the questionnaire showed an intraclass correlation coefficient 0.77 to 0.96 with a 95% confidence interval (CI 0.75-0.99). The overall response rate was 65% (n=84/130). There were 52 questionnaires that were returned by mail and 32 were filled-in by the patients during their admission into the hospital. Among 32 in-patient responders, there were 13 patients who initially did not reply to the postal questionnaire but completed it after they received a reminder during their in-patient stay.

There were 30 females (36%), 52 males (62%), and 2 respondents who did not declare their sex. Of all the patients, 94% described their ethnicity as British, 1.2% each as African and British-African, and 3.6% did not disclose. A total of 70% of the patients (n=59/84) declared to have an educational certificate, 26% (n=22) had no educational certificate, and 3 (4%) did not

answer. In 59 educated patients, 23 held a degree (39%), followed by 18 and 10 (31% and 17%) having O and A levels. Two patients had obtained a Master's degree and 2 were PhDs. Four patients did not declare the level of their qualification.

Of the patients, 87% (n=73/84) had access to a computer and the Internet (Table 1). In age group 21 to 60 years, 94% of the patients (n=60/64) had access to the Internet, with no difference in various age subgroups, and 67% of the patients (n=12/18) in age group 61 to 70 years (P = .004) had access to the Internet. Hospital doctors (n=69/84, 82%) and general practitioners (n=66, 79%) were the 2 main sources for medical and health information. Whereas the Internet was a preferred source of health and medical information for 70% of patients (n=59/84) as compared to books 17% (n=14/84, P = .003) and magazines 12% (n=10/84, P = .001). Of the health information seekers, 90% looked up information on transplantation (n=53/59) on the Internet as given in Tables 1 and 2.

In specific questions about transplant Web sites, 85% patients (n=71/84) would like their transplant team to develop a Web site for information on transplantation, and 52 (62%) would like to receive health advice by e-mail. Fifty patients (85%) commented that transplant Web sites are an effective way of obtaining information. In total, 76% of the respondents (n=64/84) wanted to include e-mail, message board (54%) (n=45), and chat room (45%) (n=38) on the Web site. The health topics suggested by the patients that they would like to see explained on a transplant Web site are given in Figure 1. Patients mentioned the following topics, which they found only on the Internet: Daily tips for living with a transplant, information for return to work after surgery, death and other statistics, pictures of kidney disease and operations, information on drugs, and patients' experiences.

Table 1. Trends of Web browsing in renal transplant patients.

Survey responses (respondents n=84/130)	Percentage and number	*P* value
Access to computer	87 (n=73/84)	NA
Access to Internet	87 (n=73/84)	
*Age 21-60 years	94 (n=60/64)	
Age 61-70 years	67 (n=12/18)	.004
Age 71-80	100 (n=1)	
Preferred source of heath information		
Internet	70 (n=59/84)	
Books	17 (n=14/84)	.003
Magazines	12 (n=10/84)	.001
Health topics searched (70%, n=59/84)	Total n=59	NA
Transplant operations	69 (n=41)	
Rejection	66 (n=39)	
Immunosuppressive medicines	59 (n=35)	
Complications	54 (n=32)	
Donor related	52 (n=31)	
Quality of life	52 (n=31)	
Transplant risks	52 (n=31)	
Survival rates	46 (n=27)	
Travel	44 (n=26)	
Exercise	41 (n=24)	

Abbreviations: n, number; NA, not applicable
*no significant difference in various age subgroups

Table 2. Patient's views on transplant Web sites visited.

Questions asked from patients (n=59) who consulted a transplant Web site for medical information	Yes n (%)	No n (%)	Do not know n (%)	No answer	*P* value
Found the required information on Web site/s?	54 (92)	2 (3)	1 (2)	2	.001
Information on Web site/s was accurate?	44 (75)	2 (3)	10 (17)	3	.001
Website/s easy to understand?	51 (86)	3 (5)	3 (5)	2	.001
Information useful?	53 (90)	1 (2)	1 (2)	4	.001
Information same to what general practitioner provided?	33 (56)	10 (17)	8 (14)	8	.002
Information same to what transplant team provided?	45 (76)	7(12)	4 (7)	3	.002
Additional to general practitioner given information?	24 (40)	26 (44)	3 (5)	6	.08
Additional to transplant team given information?	9 (15)	39 (66)		11	.003
Transplant Web sites an effective way of obtaining information?	50 (85)	6 (10)		3	.001

Abbreviations: n, number; NA, not applicable

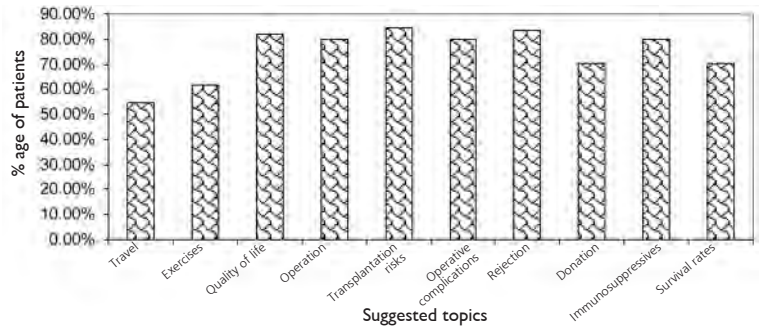

Figure 1. Percentage of patients and their suggested topics for transplant Web sites.

Discussion

In total, 87% of our study population from various age groups were Internet users, and 90% (n=53/59) of the health information seekers on the Internet looked up information on transplantation. The results of the study are based on a survey of transplant patients in the West of Scotland and show a higher Internet penetration and its use for health information as compared with previous studies. The Oxford Internet Survey 2005 in Britain showed that 37% of the study population used the Internet for health with 20% using it several times. Internet penetration in Britain was, at that time, 65%, and was growing by 3% reported between 2003 and 2005.[4] Similarly, a study carried out by the Welsh national health system surveyed 1002 people between March and May 2006 and reported that approximately 4 in 5 respondents (84%) had access to a computer either at home, work, or another location, and a similar proportion (78%) had Internet access. Around two thirds (66%) of those with access to the Internet used it to obtain health information.[5]

Our survey has shown that the Internet is a popular source (70%) of health information in renal transplant patients and is used more frequently when compared with more-traditional methods such as books (17%) and magazines (12%), suggesting a trend toward the Internet as the favored means for gathering information (Table 1). Patients not only explored topics like transplant operation (69%) and rejection (66%), but also lifestyle topics such as travel (44%) and exercise (41%), and suggested they be included in transplant Web sites as given in Table 1 and Figure 1. Most patients found the required information on the Internet, and they felt it was accurate, understandable, and useful (Table 2). Of these, 85% of the patients (n=71/84) wanted a transplant team to develop a transplant Web site, and 52 (62%) were willing to have health advice by e-mail. A total of 76% patients (n=64/84) wanted to include e-mail, message boards 54% (n=45), and a chat room 45% (n=38) on the Web site.

The Internet, over the past 10 years, has rapidly become an important source of information for patients, and more people are relying on the Internet for medical information as a result of its accessibility, speed, and anonymity.[19] However, it is becoming increasingly difficult to discern which resources are accurate or appropriate for patients.[20] We have shown that the educational material available on the Internet about liver and kidney transplants is of poor quality and requires rigorous input from health care professionals.[21-23]

Several Internet tools and scoring systems have been used to assess the quality of health Web sites, but none has proven credibility to reliably judge transplant Web sites.[24] Rather than relying on kitemarks, clinicians might usefully take more interest in filling the gaps in validity and accuracy of information available on the Internet about complex topics like transplantation. Clinicians should also recommend authenticated Web sites to their patients, which can help patients by saving time. This constructive input by clinicians may lead to more efficient use of this rapidly developing media. Transplant units should develop flexible, Web-based sources of transplant-related information. This would allow rapid adaptation to changes in prevalent practice as well as reflect the preferences of the patients.

It is acknowledged that the participants in this research were resident in the West of Scotland and it is likely that, owing to different demographics, the results might have been slightly different if the same research were done in another part of the country. It is considered that these differences would be slight. One may argue that a greater effect would have been expected if those transplant patients who did not take part in the survey owing to illness, language barrier, or technology limitations were included in the sample by a second reminder, or a face-to-face interview. However, it was not felt appropriate to remind the patients again to complete the questionnaire after the first reminder to avoid any potential disturbance. The authors feel that qualitative studies by face-to-face interviews would be a useful strategy in future research addressing the similar issues. As far as this study is concerned, from the outset, the design was based on a quantitative methodology, interviewing the nonresponders could potentially create a bias by introducing a qualitative approach in the ongoing study.[25] If some patients did not reply because they were not Internet users, it is likely that if they would start Web surfing for health information, and they might be able to benefit from health Web sites developed with the help of their peers.

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