

Special Feature

The times they are a changin'—the Internet and how it affects daily practice in nephrology

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Introduction

The times they are a changin'—this wisdom was galvanized into song lyrics by Bob Dylan in 1963 when computers were still in infancy. It took more than two decades until the humble beginnings of the web in 1989. Since then (and well in accordance with Bob Dylan's lyrics), content and use of the World Wide Web have increased and changed dramatically with now more than 550 billion documents on the web [1]. Not only has the Internet grown—the interactive component and networking have increased as well and the term Web 2.0 has been coined. We have recently reviewed what the Internet has on offer for nephrology [2]. Here, we discuss how these new technologies change and challenge our daily practice.

Patient information

To our knowledge, there are no data to show how many of our patients seek online information and google™ the diagnosis after an appointment with the nephrologist. However, from our own experience in the North West of England, we assume that many of our patients do so, at least under the age of 50 and certainly under the age of 40. Google™ covers one trillion uniform resource locators (URLs) [3] and a search for 'glomerulonephritis' retrieves 1 070 000 hits. Clearly there is a need for guidance through this at times confusing landscape and in our unit we do so through a leaflet with recommended websites [2]. These websites are increasingly popular and that of the American Association of Kidney Patients (AAKP) alone attracts 120 000 unique users per month (AAKP, personal communication). Despite all enthusiasm, a number of issues must be reckoned with. Three problems are of particular concern.

The first issue is that of quality. A systematic review is beyond the scope of this article, but two examples may suffice to cause concern: Madan and colleagues studied what the

Internet has on offer on laparoscopic bariatric surgery and discovered that only 15% of websites contained reasonable information [4]. A second and no less worrying example is the study by Welch and co-workers who scrutinized an online forum for paediatric nephrology and discovered that the most frequent providers of advice did not possess board certification [5]. While these findings raise concern about Internet-based medical information in general, they remain difficult to extrapolate to renal medicine where similar data are lacking.

The second issue is that of independence and bias. While many patient information websites are owned or sponsored by the industry, such information is often inaccessible or lacking altogether. And how about impartiality of the advice given [6]? Most sites insist on their editorial independence but lack transparent mechanisms to ensure such independence. Subtle ways for such influence are conceivable: one way of sponsoring is to provide full-text online access to articles. The industry may, for example, choose very carefully which articles they sponsor. Therefore, the selection of full-text articles may be biased already and this may not be obvious to the casual reader. Some US sites are maintained by dialysis care providers and contain advertisements. In general, one has to appreciate (and tell patients) that online resources are not usually peer reviewed and that the information may be biased in innumerable ways, even beyond those described here.

It is worthwhile to remember that anybody can post things on the Internet, amend or remove it at leisure and leave it there even if it is outdated. A striking example was provided by Keelan and colleagues who investigated the Internet video-sharing platform YouTube™ for videos on immunization [7]. They discovered that 50% of the videos on this topic were either sceptical or openly against immunization as a concept. They proposed the presence of a community of YouTube™ users who are critical of immunization [7]. This striking example reiterates that, when compared to peer-reviewed journals, editorial scrutiny, peer review and standards are usually all absent on the Internet. Patients will not normally be aware of these differences, and a useful guide for patients has been provided by the US National Library of Medicine [8].

Another issue is the ‘digital divide’ whereby individuals with a low socioeconomic status are less likely to use the Internet [9]. This is very unfortunate, given that low socioeconomic status is an independent risk factor for progressive chronic kidney disease (CKD) [10]. Elderly patients are also known to be less likely to use the Internet [11] and CKD is much more prevalent among those than among the more information technology-literate young patients. Thus, our web-based efforts to educate, elegant as they may be, might not reach those at greatest risk. We must also appreciate that access to the web differs markedly between countries and indeed continents: it is currently estimated that in Europe, 48% of the population have Internet access while in Africa it is only 5.6% [12]. Therefore, we need to appreciate that our web-based efforts to educate patients and relatives may not be suitable in every country. Next to nothing is known about the ‘digital divide’ in renal patients and further research should be encouraged. However, a study from Canada demonstrated that Internet use was much more common (86%) in home haemodialysis patients who are surely not representative of the entire renal population. In summary, we must try to avoid a ‘two-current system’ with one group having the knowledge or the means to increase its knowledge and another group lacking both.

Internet-based personal health records

The use of the Internet in medicine has now extended beyond providing information and serving as a forum for online discussion. Internet-based Personal Health Records (iPHR) include any Internet-based application that enables a patient or guardian to create, review, annotate or maintain a record of any aspect of their health condition [13].

The use of iPHR has been described in detail elsewhere [13] while the concept is somewhat ill defined with many platforms still in development. Politics are also heavily involved, and the UK government plans a universal iPHR within the National Health Service (NHS) by 2010. We would like to highlight the use of iPHR with RenalPatientView™ as an example.

This is a UK initiative that allows renal patients, or anyone they choose, to view an extract of their records as maintained by their renal unit. A similar system is in use in the USA [6]. In particular, patients can access their own test results as long as the renal unit feeds these, via an interface, into the system. At the start, some work is needed to set up this interface and costs accrue as well. The same is true if, for example, the laboratory changes its software in that a new interface will become necessary. Patients need to register to participate and provide consent at the same time. In our own unit, some 400 patients already use this system, chiefly to monitor their own laboratory results (Figure 1, panel A). Medical information is also available (Figure 1, panel B). Further uses are conceivable to enhance a renal care plan, such as fine-tuning of dietetic advice and listing the patient’s medication to enable a cross-check by the patient. In our experience, the system generates quite a bit of extra phone calls due to interest in laboratory results and particularly the serum creatinine. However, the system also stops regular phone calls from anxious transplant

recipients with stable function. RenalPatientView™ can be extended to allow booking of appointments, discussion with consultants, etc. Medical devices can link into iPHR and peritoneal dialysis (PD) as well as home haemodialysis come to mind as suitable scenarios [14,15].

Of course, iPHR such as RenalPatientView™ have many issues and problems, not least that methods need to be implemented to ensure data privacy and security. Patients also need to accept that some residual risk for unwanted access remains. Moreover, the information needs to be correct and the link to the laboratory can be problematic. Finally, there may be limits in educating patients and they may be confused by laboratory abnormalities they just do not understand.

How do patients perceive iPHR? A survey published in 2006 actually showed that in general patients prefer the use of the Internet [16] and 67% of patients wanted access to laboratory results. Many also wanted electronic reminders before appointments. Tuil and co-workers studied the use of iPHR in women undergoing *in vitro* fertilization [17]. Surprisingly, the authors found no beneficial effect on patient empowerment [18] but demonstrated three different types of users, namely ‘individual information style’, ‘generic information style’ and a ‘communication style’ [19]. They also demonstrated a correlation with coping as well as financial circumstances [19]. Transfer of these findings to the community of renal patients may not be straightforward and similar research in renal patients should be encouraged.

Finally, it is probably fair to say that the increased use of web-based technologies challenges the traditional paternalistic model of the relationship between the patient and doctor. Patients who use iPHR may know their laboratory results earlier than their physician. They may also see other physicians who are not familiar with [20], let alone part of, the system [6]. Some of these physicians may actually feel challenged by the fact that the patient is more aware of recent laboratory results than themselves.


How does the Internet change things for the health care professional?

We have previously compiled a list of useful websites for nephrologists [2]. However, the reservations for Internet-based patient information are also applicable to these websites: quality of information, quality control and commercial bias remain problematic. Bias may also occur depending on the availability of an abstract and full text access: physicians tend to favour papers with abstract and those with free full-text access. The terms NAA (no abstract available) and FUTON (full text on the net) bias have been coined.

It is also worthwhile to think about risks and benefits of the increasing instant access to an ever-increasing wealth of information and guidelines. Many of those are already available for hand-held computers and much of this will soon be available on mobile phones as well. Needless to say that keeping abreast of all the newly published renal guidelines and position papers will absorb time in an already busy physician schedule. And which guidelines is a

A

Providing up-to-date medical information for patients and healthcare professionals

Renal PatientView 

Home	Patient Details	Patient Info	Medical Info	Results	Medicines	Letters	Contact	Help
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logged in as: **testhd** [log out](#) 11 Sep 2008

Result panels: 1 2 3 4 ≥ ≥1

Test results for RPVHD TEST											
Date and time	Label	Urea	Creatinine	K	Ca	AdiCa	PO4	Hb	whc	plats	eGFR
06/07/06 18:35		4.3	225	3.3							28.6
06/07/06 07:30		19.2	724	5.3	2.37	2.52	1.18				7.4
06/07/06								145.	6.6	180	
08/06/06 18:25		2.6	196	2.5							33.5

B

Providing up-to-date medical information for patients and healthcare professionals

Renal PatientView 

Home	Patient Details	Patient Info	Medical Info	Results	Medicines	Letters	Contact	Help
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logged in as: **testhd** [log out](#) 11 Sep 2008

The links on this page are to information that is mainly written for patients, but it is often very useful for healthcare staff too. Almost all links are to other websites. These links have been chosen by us, but the information is not written by us.

Patient Information Links for RPVHD TEST		
Primary Diagnosis:	IgA nephropathy	IgA nephropathy for patients (IgAN Network) IgA nephropathy (NKF) IgA nephropathy (EdREN) Blood pressure and kidney disease (EdREN) Chronic renal failure (EdREN)
Treatment:	Haemodialysis	Info on haemodialysis from the NKF From the Kidney Patient Guide, with animations Info on haemodialysis from EdREN Diet for people with kidney disease
Further information		Kidney info from the NKF Kidney words explained (EdREN) Kidney and urologic diseases from the NIDDK See all our info links (on all diseases and treatments)

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Fig. 1. Screen shot from RenalPatientView™; panel A: laboratory results; panel B: patient information.

renal physician in, say, the UK supposed to adhere to—the national ones, those of the European society or rather those endorsed by international societies? Hypertension is a good example in that UK guidelines from the National Institute of Clinical Excellence (NICE) compete with the British Hypertension Society, those of the European Hypertension League and the Joint National Committee in the USA, to name but a few.

Apart from providing information the Internet may also change the way we make a difficult diagnosis: Tang de-

scribed the use of Google™ to solve the notoriously difficult cases published in the New England Journal of Medicine and reported that Google™ came up with the correct diagnosis in 54% of cases [21]. Accordingly, the authors proposed the use of web-based searching to diagnose difficult cases.

Interestingly, a ‘digital divide’ may also exist within the medical community whereby access to the Internet and its use are not universal amongst physicians. A recent study has demonstrated less Internet use in smaller and rural practices

iWANTGREATCARE.org
Choose the very best doctor for you and your family

Dr [blacked out]
16%

Trust
Listen
Recommend

Specialities:
• General Practice

Alert me when this doctor is reviewed
[Email link to this page](#)

Location:
[blacked out]

Latest reviews for Dr [blacked out]
(1 review in total)

If you are Dr [blacked out]
[Alert me when a review is added](#)
[Edit my information](#)

Prev 1 Next

Trust	20%	Added by: Patient	23 Jul 2008	Report this review
I had two appointments with Dr [blacked out], within two months, during which this doctor listened to me in				

Fig. 2. Screen shot from IwantGreatCare [24] (doctor's details blackened).

in North Carolina [22]. A similar study in Orange County, California, questioned the digital divide in doctors' offices and showed that primary care offices located in poor and minority communities in a large, suburban county had high levels of access to and interest in web-based systems [23]. In any case, we should be vigilant towards a digital divide in the renal community.

We should also be aware of the fact that patients may not only google™ their disease: they may also look up their nephrologist. Surely nephrologists perceive the need for some form of 'marketing' within the renal scientific community. However, we should also be aware that patients may take an interest as well. Again it is largely our choice whether our patients will read a random mix or whether we want to provide a website that provides the information we want them to have. It is not surprising that such communication has now become interactive with patients rating their doctors in websites such as IWantGreatCare in the UK [24]. This website enables patients to anonymously rate individual doctors with sliding scales rating trust, listening ability and one measuring how highly the user recommends the doctor. There is also a free text box asking the user to share their experience in as much detail as possible (Figure 2). Needless to say that such an approach is full of problems: the rating may be skewed by allies of that individual practitioner or by the doctor himself if he or she submits votes under disguise [25]. Also, how valid is the unsatisfactory rating for the doctor captured in Figure 1, given that only a single patient contributed? What if somebody raised serious

concerns about a particular doctor—are there mechanisms to investigate these matters? It is also worthwhile to note that defamatory remarks may live forever within the Google™ cache, even after the hosts have removed them. The legal implications of such remarks are equally unclear. The use of social networking (e.g. Facebook™) is also increasing among renal patients and a casual visit to these sites demonstrates that patients freely discuss not only treatments but also favourite (and less well liked) physicians. Again, the digital divide will play a role in online rating of physicians in that only patients who are proficient in using the Internet will be able to contribute. Is it conceivable that doctors will one day, be that subconsciously or deliberately, offer preferential treatment to potential contributors (the young web-literate professionals) while the others draw the shorter straw? Of note, even governments are now embarking on the idea of online rating of doctors and the UK government has just announced plans to introduce web-based rating of general practitioners this year [26].

Conclusion

The use of the Internet has undoubtedly benefited doctors and patients although we are sceptical that it did 'improve the productivity of providers, reduce the number of office visits, and save money' [27]. No doubt, the Internet holds great promise and dangers at the same time. We as the renal community are not directly responsible for all the

information that is on offer but our patients will benefit if we provide some form of guidance though this plethora of information [28]. The Internet may also allow for on-line health records and new ways of communication with patients, including access to laboratory results and clinic letters. This new technology challenges a paternalistic concept of care and some may fear the patient will cross the line to become a citizen consumer. In any case, a framework of educational efforts is required so that patients understand what they can now access. Finally, it should not escape our attention that we can use the Internet as a marketing tool to reach the public and decision makers, given that kidney disease is probably under-represented in the media [29].

Conflict of interest statement. None declared.

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