

Patient perspectives on health advice posted on Internet discussion boards: a qualitative study

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Abstract

Background Use of the Internet for health information by patients is growing, and there have been diverse responses to this both within the research community and the medical and health-related professions. The use of Internet discussion boards are one way that people living with long-term conditions can interact with their peers and offer and seek advice, support and information. We report patient perspectives on using a discussion board within a wider pilot study of an Internet-based self-management system for diabetes.

Design Qualitative data was gathered during three stages of developing and piloting the wider self-management system. These are: (1) patient focus groups as part of a stakeholder consultation; (2) a pre-test session and focus group; and 3. a 6-month pilot study including follow-up individual interviews.

Results Three main themes were identified within participants' perspectives on Internet discussion boards. First, a focus on the importance and value of peer support to these patients. Secondly, participants' awareness of the need to evaluate the information posted by others in light of their own circumstances. Thirdly, the value placed upon the experiential knowledge of others living with the same condition.

Conclusions Many people living with long-term conditions would like to be in contact with their peers, and Internet discussion boards represent a cost-effective and interactive way of achieving this. Within the context of diabetes, the knowledge and expertise accumulated over many years of self-management is central to participants' self-reported ability to evaluate information posted and make decisions on its possible use.

Background

There are over 2 million people in the UK with diagnosed diabetes and Internet-based interventions may be used as a tool to help these

individuals self-manage their condition. Recent research shows that 15 million homes in the UK had Internet access in 2007, and this is up 1 million from 2006.¹ Within this general increase in usage, one important way in which

the Internet is being used is in relation to health with data showing that 68% of the UK Internet using population have used it for health information.² There have been several recent studies of Internet-based interventions in diabetes carried out in Europe³⁻⁶ and North America.⁷⁻¹⁰ We developed and piloted such an intervention (The Virtual Clinic) targeted at people receiving care for diabetes from the UK National Health Service (NHS). The Virtual Clinic was comprised of three core features: (1) secure messaging between patients and their health professionals; (2) an information portal linking to other web-based information; (3) an asynchronous discussion board for peer-to-peer advice and support. These tools, with their benefits of interactivity, wide accessibility and low marginal cost, represent an opportunity to support patients. In particular, the Internet offers easy access to peer-support, which is a feature routinely identified as important and valued by patients.^{11,12}

The Virtual Clinic was grounded in the behavioural theory of self-efficacy.¹³ The theory suggests that to enhance self-efficacy (the confidence an individual has that they can achieve a particular objective) an intervention should increase autonomy, reduce negative perceptions of being different, offer vicarious learning and modelling opportunities from peers, encourage setting of achievable goals and give rewards for such achievements. Enhanced self-efficacy, in turn, increases the implementation of successful self-management. We have previously published the broad findings from the stakeholder consultation,¹⁴ and a summary of the pre-test session.¹⁵ However, in this paper we focus explicitly on the patients' views on the use of an Internet-based peer-to-peer discussion board, their accounts of their approaches to using this facility, and their perspectives on the relationship between this and advice received from health professionals. In contrast to many other studies exploring lay use of the Internet for health information more generally, our study is located within a purpose-built and dedicated self-management intervention which participants could only access through involvement in our research

project. The multi-source nature of our data collection methods mean that we are uniquely placed to combine focus group discussions of how participants reported they engage with discussion boards more generally with post-study interviews of how participants reported they engaged with the Virtual Clinic discussion board in particular.

The developing role of the Internet in health care has prompted differing reactions. Nettleton, Burrows and O'Malley¹⁶ suggest three types of response to increased Internet use for health by lay people. First, a celebratory and empowering response, which they suggest comes mainly from sociologists, values the perceived potential to recalibrate power relations between patients and health professionals. The supposed 'democratic imperative of the Internet' offers opportunities for empowerment and fostering of patient and lay expertise, whilst also creating virtual spaces for resistance to dominant medical practices. Second, a concerned and dangerous response, which comes mainly from the medical profession and is concerned with the potential additional demands on professional resources and the supposed poor quality of much online information. Third, a contingent and embedded response (favoured by Nettleton *et al.*), which suggests that lay people are able to make reasonable assessments of online health information and focuses on how Internet health use meshes with other health information seeking practices and may therefore complement formal health care rather than represent a challenge to it. This perspective is rooted in empirical studies focused on the routine use people make of the Internet within the material contexts of their everyday lives, and how Internet use is often contingent upon health needs and particular conditions.^{17,18}

Methods

The data presented here were collected as part of the wider project to develop and pilot the Virtual Clinic Internet-based self-management system for diabetes. This work consisted of three main stages: (1) a detailed consultation with

stakeholder groups, including focus groups with patients; (2) a hands-on pre-test session with patients, followed by a focus group; (3) a 6-month pilot study, including follow-up interviews with a sub-sample of patients. Only the collection of qualitative data from patients on their views and experiences of the Virtual Clinic is described here. The particular group we worked with were adults who used an insulin pump to manage Type 1 diabetes. The initial stakeholder consultation stage was reviewed and given a favourable opinion by the Warwickshire Local Research Ethics Committee. Three focus groups were held with a total of twelve patients recruited from a local diabetes clinic and each group had between three and five participants (two male and ten female). Focus groups were conducted at the Education Centre within the hospital at which the clinic was based, making a convenient and familiar location. At each group a short demonstration was given to familiarize participants with the kind of intervention concepts we were developing. The focus group schedule then focused upon: participants' initial reactions to the concept, the most and least important/useful elements, whether they would be likely to use such a system, factors that may facilitate or hinder use, what the benefits may be, and any concerns they may have. Sessions were audio-recorded and transcribed in full. The pre-test session and pilot study were both reviewed and given a favourable opinion by the West Midlands Multi-centre Research Ethics Committee. The pre-test session was undertaken to evaluate the intervention in terms of feasibility, acceptability and effectiveness prior to the start of the pilot study. Five patients (all female) took part in the pre-testing and were recruited from the three clinics who had agreed to participate in the subsequent pilot study. The session involved a hands-on element of about 30 min, in which users were introduced to the system and asked to experiment with it, followed by a focus group in which they gave their feedback. The focus group was audio-recorded and transcribed in full. Finally, the pilot study involved seventeen patients from the three clinics using the intervention over a period of 6 months. Individual

interviews were carried out at 6 months with a purposive sub-sample of five participants (one male, four female) selected on the basis of age and their level of activity within the Virtual Clinic. The interviews focused on participants' experiences of using the Virtual Clinic over the study period. All interviews were audio-recorded and transcribed in full.

The focus group transcripts from the stakeholder consultation were preliminarily analysed independently by two investigators using a thematic analysis approach. Recurrent themes were identified as they emerged from the data, rather than on the basis of researcher preconceptions. Following this, the two met to compare and discuss the emergent themes. Patients' views and experiences on the use of discussion boards were just one theme to emerge from these wider focus group discussions and the broader findings are reported elsewhere¹⁴ (others themes included: electronic communication between patients and health professionals; how an Internet-based system would fit with their current clinic-based care; the kinds of people that would use an online system; and the preferred design, features and functionality). However, the use of discussion boards was a key theme identified within the data, and an area which we wanted to explore in more detail. To that end the pre-test focus group transcript and the individual interview transcripts (which again all dealt with patients' views and experiences of the Virtual Clinic more widely) were examined by the first author for instances of discussions in this area. The combined data extracts from these three stages of the research were compiled and subjected to a similar thematic analysis to that already detailed above.

Findings

The findings are described below in terms of the main themes that emerged from the patients' talk about the use of discussion boards. Extracts from the data are used to illustrate the points being made, and extracts were selected on the basis of being particularly clear and/or concise examples. Each extract is followed by a

descriptor which indicates gender of the participant and the research stage from which the extract is taken (i.e. stakeholder consultation, pre-test session, pilot study).

Importance and value of peer support to patients

The peer support available through the discussion board feature was one of the most valuable elements of the Virtual Clinic system identified by patients, and this supports findings from other studies.^{7,11,12} Patients identified two key benefits in particular: first, the ability to pick up tips and suggestions for managing their diabetes from peers, even for those who had had the condition for some time; and second, communication with someone that understood what they were going through, particularly for those who did not know others with diabetes. The first extract below focuses on encountering new issues, even when an individual has had the condition for a long time, and the participant describes using the discussion board as a starting point for thinking through what might be going on:

‘but there are so many things that you can come across for the first time and the one I had to seek advice on was the flu injection last year, which caused chaos and I thought, ‘well is this the flu injection or is there something else that I’m missing?’...but again a (discussion) board like this, just to push the question in and see what response you get back’’ (Male, Stakeholder Consultation).

At a later stage in the research, and after having used the discussion board throughout the 6-month pilot study, the same participant also reflected on the value of finding that he appeared to be as knowledgeable and informed as other patients in the study. He stated that it can be equally useful to find there is nothing new for you to learn about as it can be to discover new information, and that establishing this can build confidence in diabetes-related decision making:

‘Sometimes it can be useful if you find out nothing that you didn’t know before, if only for the reason that you now know that there’s nothing else that you need to know, so you can find out nothing, which is very useful because now you know that

whatever decision you make in these circumstances, there’s nothing else you ought to be taking into(account)’ (Male, Pilot Study)

The extract below highlights the role of an Internet-based discussion board in facilitating communication and interaction with others living with the same condition. This was discussed by the vast majority of patients as few seemed to know others with diabetes and felt that their families and friends could not fully appreciate what they were going through. The extract used below deals with the participant’s experiences of managing her insulin pump, but discussions were not limited to this aspect of the participants’ experiences and other examples dealt with diabetes more generally:

‘I must admit even now and I’ve been on a pump for about three years, you can feel very, very isolated if you haven’t got somebody you can literally talk to or email to or whatever, who’s got another pump...you know...to ask them ‘Have you had this problem?’ and when you actually talk to diabetics on pumps, you find we all have the same problems...You know... it’s so nice to feel that you’re not on your own. Your problems aren’t just you messing things around and getting things wrong’ (female, pre-test)

Proceeding with caution

However, although patients welcomed the opportunity to communicate with their peers, and to seek advice and support from them, this was not at the expense of learning how to manage their own condition and how it affected them as individuals. Patients reported feeling very aware of how diabetes affected them personally, and how this may differ from others with the same condition. The following are two typical examples:

‘Yes but I think the whole thing about diabetes is I think it is very, very individual to the person who’s got it’ (Female, Stakeholder Consultation)

‘I do believe...that we’re all different and you do know your own body. Well, you do once you get to know it.’ (Female, Stakeholder Consultation)

The knowledge and experience built up from managing their diabetes on a day-to-day basis

was felt to be substantial, and patients spoke at length about the need to evaluate suggestions posted on discussion boards in the light of their personal situations, and perhaps to proceed with caution.

What follows are two fairly typical extracts from patients, and these illustrate the kinds of strategies or approaches patients say they have used, or would use, when consulting fellow sufferers through an online discussion board. The first extract comes from someone who has used other discussion boards in the past:

'I've used these many times. I mean if for instance, the problem with... shall we say if we had time... well, I would have done it and put the question in to Google and I'd have finished up on a board just like this and very often you read down and there's somebody with the same problem and four or five different answers to it and you make your mind up which... or try all four... at least it gives you somewhere to start' (Male, Stakeholder Consultation)

This patient describes how he would draw upon his own knowledge and awareness of his condition and how it affects him to help him decide which, if any, of the suggestions found might work for him. The discussion board is not therefore regarded as something that will provide hard and fast solutions to a problem, but instead it gives him somewhere to start with thinking through how he is going to approach his problem. This idea is reminiscent of the contingent and embedded 'third way' suggested by Nettleton, Burrows and O'Malley¹⁶ in that this individual suggests he will take the suggestions found on the discussion board and evaluate them in the light of other relevant information or knowledge he already possesses.

In a similar way, this second extract stresses the importance of being informed, and gaining as much information as possible:

'The more information you can get the better. You learn very quickly that just because it worked for somebody else it won't necessarily work for you, but you can always start to think in that direction and you can always try it' (Female, Stakeholder Consultation)

What this extract demonstrates is that, rather than representing a definitive answer or

end point to a problem, responses on a discussion board may instead represent a starting point for the individual. In this way the use of discussion boards is not so much about passive acceptance and enactment of others' suggestions, but more about the active and reflective engagement with one's own condition. For example, someone may post their experience of changing what they eat at various times, and whilst that particular dietary change may not work for someone else, looking again at what they eat and when may help them solve their particular problem.

The strategy of simply rejecting advice posted was also discussed and the majority of participants reported an awareness that some of the information posted may be problematic. The following extracts are two good examples of how respondents highlighted the active role individuals must take in evaluating information :

'What if you get people though who are giving you wrong advice? I mean... you know... you could get somebody coming in and saying 'Well, I only increase my insulin by one unit when I have a cold' you know? Or... but I mean you've got to be able to select and think 'Well, I don't think that's quite right.' (Female, Stakeholder Consultation)

'It's good to read what other people put but you don't necessarily have to take the advice.' (Female, Stakeholder Consultation)

Valuing experiential knowledge

It is interesting also to think about the kinds of information that people are seeking. In a study of online health-information seekers, Kivits¹⁹ found that there was a very 'everyday dimension' to the information people were seeking, and that 'experiential knowledge' was valued, sometimes above medical expertise. These two extracts from our study also draw attention to the value placed upon information received from those with direct experience of living with the condition (in this case diabetes):

'I'm not saying the doctors are no use and I wouldn't ask them anything, but there are certain types of question I would ask them and other types

of question where I would go to other users first and I know where I'd be most likely to find the answer' (Male, Stakeholder Consultation)

The following extract comes from a woman who had used the discussion board to seek the advice of other patients on taking a break from her insulin pump whilst on holiday. The advice from fellow pump-users had been not to do this:

So you think, 'Well fair enough' you know, 'Just carry on', but it was lovely being able to actually get an answer directly back from someone who had been there and tried it out, rather than speaking to a consultant or one of the diabetic (nursing) sisters'" (Female, Pilot Study)

Our data does not suggest that this experiential knowledge is routinely privileged over and above medical expertise; rather that it is complementary to it. As the first extract suggests, it seems there are certain types of information that patients feel it is more appropriate to seek from a health professional, and other types of information they feel it is more appropriate to seek from other users. This again supports the 'contingent and embedded' third way¹⁶ of conceptualizing how patients' use of the Internet for health information can mesh with other health information gathering practices in a complementary way rather than undermining them. As they become more skilled in managing their diabetes, individuals appear to identify different kinds of information needs and develop views on who they regard as the most appropriate provider of that information. The discussion board facility within the Virtual Clinic provided an important and valued medium through which participants could seek advice and support from their peers.

Discussion

Patients are often keen to be in contact with others living with the same condition. This is a key finding from our research in diabetes and also from other studies both in the same and different areas of health care.^{11,12,14,20} However, it is important to recognize that not all patients wish to engage in this activity and that the desire for social support may vary across different ill-

nesses or conditions.²¹ In addition, the participants in our research were all using insulin pumps and therefore represent a particular subgroup within the wider diabetic population. This, combined with our small sample size, may restrict the generalizability of our findings and limit their applicability.

However, for those individuals who do desire such peer-to-peer contact Internet discussion boards of the kind we studied in this project represent a cost-effective and interactive way of facilitating this. Much of the information and advice that patients are looking for is drawn directly from the experiences of others and is not necessarily something that can be provided by a health professional. The desire to seek out and hear about other people's experiences is often a central element of patients' use of the Internet for health information. For example, Powell and Clarke's²⁰ work with mental health-service users identifies three key patient-perceived benefits of such activity as: an understanding of universality; the instillation of hope; and finding understanding and empathy. The benefits of finding out, or being reassured, that one is not alone (universality) and that others are facing similar problems but finding ways to overcome them (instillation of hope) are central to the majority of our data. Finding understanding and empathy is also important here, and also in the later section of this paper on the most appropriate sources from which to seek information.

A recent study explored a computer-mediated social support and advice forum for people with diabetes, similar to that we used in our work.²² Many of these discussion groups exist and provide people living with a particular condition the opportunity to share experiences, offer advice to others, and give and receive practical and emotional support. The forum studied contained largely well-informed participants who routinely used it as an aid to the reflexive management of their diabetes. Much of the forum discussion was of a technical nature and involved issues such as drug regimes and diet. Some of these exchanges were concerned with challenging orthodox medical views and advice. The study authors note that living with diabetes can be highly individualized

and highlight the importance of reflexive management on the part of the patient, taking into account their personal experiences and life chances. Within our study patients reported using their expertise in managing their own diabetes to appraise information posted by peers and to evaluate whether it was likely to be helpful or useful to them. The knowledge and experience they felt they had built up from managing their diabetes on a day-to-day basis was regarded as substantial, and patients spoke at length about the need to evaluate suggestions posted on discussion boards in the light of their personal situations, and perhaps to proceed with caution. In an earlier section of this paper we explored the ways in which participants reported they may make selective use of information and advice posted, or even disregard some elements if they felt they were inappropriate or incorrect. We would like to make clear that we are not presenting these reports as necessarily what these patients *actually* do when they are using discussion boards of this kind in the privacy of their own homes; instead these are patients' *accounts* of what they (would) do. It should be noted though that these discussions around how to manage information and advice posted on discussion boards occurred spontaneously, and were not prompted by the focus group facilitator or interviewer. This suggests that these accounts are not, primarily at least, attempts to deflect charges of inability to appraise the quality or accuracy of information appropriately. Exploring what patients actually do with the information they find on such Internet discussion boards was beyond the scope of our study.

There remains however a concern in some quarters about lay people's use of the Internet for health information, and debates in this area are ongoing, especially regarding quality control. Although the concern appears to come more from health professionals than from the lay users themselves.²³ A recent systematic review of the effects of online peer to peer interactions within comparative studies found no evidence to support concerns of them causing harm, although also failed to find robust evidence of health benefit.²⁴ Existing research has

also shown that most information posted on boards of this kind is accurate, or very quickly corrected by other participants;²⁵ and also that sometimes medical experts can disagree when rating the quality of health information found on the Internet.²⁶ This indicates that the concerns voiced by health professionals within the 'concerned and dangerous' response characterized by Nettleton *et al.*¹⁶ may be largely unfounded in our sample of people living with diabetes. However, as we have shown, our participants drew heavily on the expertise they had developed through managing their ongoing condition over a long time period and it may be that our findings are not transferable to others with more acute conditions or those with long-term conditions that do not require the same amount of daily self-management and maintenance.

Within our sample we found support for the 'contingent and embedded' response.¹⁶ This represents a 'third way' suggesting that, for the most part, lay people are well able to make reasonable assessments on appropriate information. Internet information seeking meshes with other approaches to seeking help and advice, and is prompted by specific health needs. Internet-based information sought from, and provided by, peers may therefore complement the advice and support provided in formal health-care settings rather than posing a challenge to it. The Virtual Clinic self-management intervention (which formed the basis of our wider research) combines access to advice and support from peers with a messaging service for convenient contact with patients' own local health professionals between routine clinical appointments. Our data shows patients value this additional support from peers and a dedicated online community within a wider intervention linked to local health services is an acceptable way to deliver this.

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