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Patient information needs: pre and post consultation

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ABSTRACT

This paper presents findings from a study of information behaviour by National Health Service patients which explored motivational triggers for information needs. Previous research has highlighted the importance of contextual elements in users' changing information needs. This paper highlights how those needs may centre on specific events: in particular, a patient's consultation with their doctor. Patients initiate information seeking to assess whether they need clinical intervention, in preparation for the patient-doctor consultation and to verify the diagnosis or treatment stemming from that consultation. The study has revealed that having confidence in health practitioners is one key motivation for information seeking. Another is a desire to use health service resources judiciously, efficiently and effectively.

Keywords

Digital Libraries, Information Needs, User Study, Patients, Health Information.

1. INTRODUCTION

With the growth of electronic information and the increasing availability of health information, the idea of the 'informed patient' has become prominent. On the one hand, this has resulted in concerns about associated changes in the doctor-patient relationship and health outcomes [1]; on the other, it has given rise to visions of timely, high quality, accessible, understandable, reliable and relevant information for patients and carers [2]. Certainly, a shift is occurring in access to knowledge and, with it, access to power [3]. In this respect, digital libraries are at the heart of technological and social change.

To design useful information systems with appropriate practices and policies, it is necessary to have a sophisticated understanding of how resources, whether electronic or traditional, relate to current and future user needs. However, the experience of illness and its treatment can be complex. Patients' information needs will inevitably change and evolve in response to changing situations. A digital library that is accessible and fulfils patients' needs, we argue, is one whose design is configured around patients' situations, experiences and needs. Consequently, it is important not only to understand patients' information needs, but also to understand those needs within the wider context in which they arise.

The findings reported in this paper derive from an interview study conducted with a sample of National Health Service patients. The aim of the study was to gather accounts of information seeking and use, to explore how those needs were motivated by the situations people found themselves in (physical, cognitive, social or otherwise), and to explore the impact of patient information seeking on the health practitioner–patient relationship. In this paper we report the nature of information needs and what motivates those needs.

Previous research has highlighted the importance of temporal factors in understanding users' changing information needs [4]. In the study reported here, the clinical consultation emerged as a significant contextual event against which patient information seeking can be referenced and understood. This therefore provides the main theme and organizing principle for the paper.

In the next section we briefly discuss background to the study. In section 3 we describe the study method, and in section 4 we report the results. We conclude with a discussion of our findings.

2. BACKGROUND

In information behaviour research, there has been a growing recognition of the information user's context as constituting a vital frame of reference [5]. Information behaviour does not occur in a vacuum, but arises from and is conditioned by circumstances. Consequently, the context for information seeking behaviour provides an explanatory framework for meaningful interpretation and also for generalization. It locates the role of information seeking within an unfolding personal and social history, and provides a framework for generalization by suggesting prior circumstances which may be predictive. As Vakkari, Savolainen and Dervin have argued, context provides the necessary conditions for understanding information needs and behaviours [6].

Whilst many things can be, and have been, understood by context, it has been argued that digital library (DL) designers must appreciate the social elements of information behaviour to avoid digital libraries being limited to the role of 'passive warehouses' [7, 8]. Healthcare represents a social context for information seeking and use which can give rise to new understandings about health as well as information needs.

2.1 Contextual triggers for information needs

Recent research has considered how information needs arise and how people make sense of information in the light of their wider needs – for example, interpreting the significance of information in relation to a work task [9]. Some researchers [10] have described 'cycles of activities' to make sense of the context within which digital libraries exist. Such cycles include phases in which information is accessed, leads to other information, is stored (e.g. within another DL), is disseminated to other people and is preserved. However there is very little research on what triggers users' information needs and how those triggers interact with

searching, accessing and interpreting information. Adams and Blandford [4] discuss a cycle of initiating needs, searching and interpreting information that they term an ‘information journey’. For example, a health scare reported in (and promoted by) the national press can initiate information requirements for patients and the need for support in interpreting that information.

Fisher [11] highlights the importance of context and location in information behaviour for digital libraries. ‘Information grounds’ [12] are described as environments triggering informal and serendipitous initiation of information requirements and exchange of information. In particular, Pettigrew [12] studied a foot clinic, and identified exchange of knowledge with both clinical professionals and other patients as informal stimuli for information requests. However, these accounts centre on information needs and exchanges within this location and the related event. The question remains as to what triggers information needs that are not location dependent.

There has been a wealth of research on the librarian consultation as both a support and a trigger for users in their identification and specification of information needs. Metoyer-Duran [13] identified two types of information consultation, with the librarian acting as a ‘broker’ (providing information access) and an ‘information professional’ (providing information integration and transformation). Several other researchers have highlighted the importance, for end-users, of the ‘information problem detection’ role taken on by librarians [14, 5]. Here the librarian, it is suggested, acts as a kind of psychotherapist whose skilful questioning supports the user in understanding their own needs and then supports them in meeting those needs. Within the clinical domain it could be argued that the clinician takes on similar roles.

Theng et al [15], in particular, argue that current digital library designs provide limited support for this need. However, again, all this research reviews information needs within the event of the librarian–user consultation. In this paper we propose the ‘health consultation’ as a trigger for information needs both before and after the event.

3. METHOD

Two groups of 8 patients were interviewed. The first group was selected from a Patient Advice and Liaison Service (PALS) patient panel attached to a hospital in the South of England. The patient panel holds regular focus group meetings to feed back on various aspects of the hospital’s activities including the design of patient information. The second patient group comprised mature students studying towards an MSc. in Human Computer Interaction. The two groups were of contrasting ages, with the first ranging from 43 to 81 years (average age 64 years) and the second ranging from 25 to 42 years (average age 31 years). Semi-structured interviews were used lasting between 30 minutes and an hour. These interviews were based around a set of non-standardised prompt questions intended as a starting point for eliciting detailed accounts of specific health information seeking episodes and their relationship with ongoing healthcare.

An in-depth analysis of respondents’ perceptions was conducted using the Grounded Theory method. Grounded Theory [16] is a social-science approach to data collection and analysis that combines systematic levels of abstraction into a framework about a phenomenon which is verified and expanded throughout the study. Once the data is collected, it is analysed in a standard Grounded Theory format (i.e. open, axial and selective coding and identification of process effects). Compared to other social science methodologies, Grounded Theory provides a more focused, structured approach to qualitative research. The methodology’s

flexibility can cope with complex data, and its continual cross-referencing and analysis of emergent themes allows for grounding of theory in the data and the uncovering of previously unknown issues.

4. RESULTS

Before discussing details of the participants' information needs, and how these related to clinical consultations, we first introduce a factor that emerged during the study as important for explaining a number of aspects of the health information seeking discussed by participants: the general level of confidence that participants had in their healthcare professionals. Participants expressed varying levels of confidence in their healthcare professionals' judgements, and in various ways this formed a motivation for information seeking both before and after the consultation. Concerns were evenly spread across the two groups interviewed.

Various reasons were given for patients' poor confidence levels. For example, it was perceived that health practitioners may lack a concern for more holistic healthcare factors such as: addressing the underlying causes of illness, addressing impacts of treatment on lifestyle, and considering potential interactions of treatments with other conditions and their long-term side effects. Also, it was thought that resource limitations might overly constrain the extent of tests and treatments offered. One participant expressed this as follows:

Participant: "I did some separate searching. As always, I always doubt the doctor [laughs]"

Finally there was concern about perceived limitations in current medical knowledge or, more specifically, the practitioner's knowledge. For example,

Participant: HRT. I'm very suspicious. I don't think doctors know enough about hormones... And so, they say you need HRT, er... I'm not going to launch down that path unless I read something much more reassuring.

and...

Participant: I don't believe any expert can always be 100% up on the current knowledge of everything to do with all different things especially medical... it's so fast paced.

With this context, information needs could be divided into the kinds of needs and motivations that occurred prior to a clinical encounter and those that were triggered by the encounter and therefore occurred after it.

4.1 Seeking health information in anticipation of a clinical encounter

In this section we discuss occasions reported by the participants in which they specifically sought information in anticipation of a clinical consultation. Pre-consultation, however, does not necessarily mean pre-diagnosis. Participants described seeking information prior to a consultation for three main reasons: assessing the need for consultation, deciding who to see, and preparing for the consultation.

4.1.1 Am I ill?

An initial motivation for seeking information in advance of a clinical consultation was to establish whether a consultation was necessary. Advice was sought from help lines (e.g. NHS Direct), from knowledgeable peers, or from the Web. For example:

Participant: You're trying to decide whether you need to be seen, so then you can not need to go as a result of having done the research.

One participant described seeking information on the Web to demonstrate to a friend that they needed medical help.

Participant: ...there's a couple of times when I've found information out for other people based upon blood pressure... or a bloodshot eye, which... the bloodshot eye was actually quite good because... I managed to prove to the other person, who didn't believe it was serious, that it was very serious and they should have gone, and they did, and they ended up being hospitalised straight away.

Conversely, others were able to reassure themselves that further consultations were not required.

Participant: I've also researched melanomas on the Internet, so that I did at one point get ... a mole that looked like it was changing color and looked like it was changing shape. So I researched that on the Internet and found enough information to put my mind at rest... to know what to look for... to know how much it had to change and what it had to be like before it was enough of an issue to go and see a GP. So that meant that I didn't have to go and seek medical advice.

Participants described the goal of this initial information seeking as an attempt to arrive at a potential explanation of their symptoms, i.e. possible diagnosis.

Participant: ... because I twisted it about a year or a year and a half ago, and I started jogging and it started becoming a little bit sore, so I think I had a look on the Internet to see what ... why it that might be.

Participants frequently noted concern that their actions might cause an unnecessary drain on National Health Service resources. An important rationale behind assessing the need for medical help was to avoid wasting health service resources (as well as their own time) on minor complaints not requiring treatment.

Participant: So I would phone them [NHS Direct] then [midnight] just to get whatever information I wanted to. They might say "Send for a doctor", "Get an ambulance" or "don't worry". [...] Oh I've found them excellent. I really do. 'Cos you try not to send for a doctor unless you have to... especially at midnight.

In contrast, others expressed a need to avoid seeking information about potential diagnoses, recognising their lack of experience in making such assessments and wishing to avoid unnecessary anxiety.

Participant: I have this feeling that people who check it [The Web] are just going to get more scared than helped, but I suppose it's one resource that you should have. I guess it was the same with health encyclopaedias and books. I'm sure that if you just read a few of them you would have like 50 complaints that you know hadn't been addressed. So, you're just scaring yourself.

Having satisfied themselves that there was a need to consult a health practitioner, the next question was often who to see.

4.1.2 Who can help me

Following a previous diagnosis, some participants described seeking information in order to identify specialists who could provide the best treatment. For the most part, these participants wanted treatment for quite specialised conditions or circumstances; for example, participants specified requirements to locate specialists in high blood-pressure in Caribbean people, and in polycystic ovarian syndrome.

One motivation for seeking out a specialist, outside of standard referrals, was a concern that referrals through a GP could be limited by geographical differences in resource availability.

Participant: And still today there are some issues... what we call the postcode lottery er... where even what is judged to be affordable in one particular hospital er... is judged to be unsuitable somewhere else. So I was keen to find out what was the best solution to my problem. [...] I would have judged that there would have been limits on budgets and there would be limits on erm... availability of any particular linking hospital and the personnel working there erm...

Having identified the need for a consultation and who to see (with or without reference to electronic information resources), there was often a desire to be well prepared for the consultation.

4.1.3 How can I prepare?

Some participants described seeking information in order to prepare themselves for a clinical consultation. Within this broad category, information and the understanding it provided can be described as have two contrasting, yet complementary, roles. The first was to enable them to become a partner in their healthcare by contributing more usefully to the consultation situation (and thereby reducing demands on Health Service resources). The second was to enable the participant to be more questioning in the consultation. In both cases, understanding their condition, treatment options, and how these might relate to their own specific circumstances were important.

For some participants, the value of pre-consultation information seeking, and the knowledge derived thereby, helped them anticipate practitioner information needs regarding their symptoms and lifestyle in order make an efficient and effective diagnosis.

Participant: So, there may be things that he or she needs to know from the diagnosis perspective...and you need to be aware of what they are...And you can suddenly rule out maybe two or three tests, which would have cost either the NHS or yourself a few thousand pounds just from knowing a little bit more about what's going on inside your body.

and...

Participant: I mean, something like a sports injury or something like that, the more you look into it, the more you know what some of the problems are. So, for example, erm... you can say what sort of sports you have been doing, even things like running shoes. If it's an old pair of running shoes – that sort of thing. So, I think you can be more ... I guess yeah, more helpful actually in the diagnosis and... getting the diagnosis as quickly as possible.

Similarly, where a condition or problem had been previously diagnosed, a basic understanding was regarded as important for reducing the time a practitioner would need to spend explaining things. This was understood as allowing more time in the consultation for joint decision-making and improving the participant's relationship with their doctor. For example, a participant who had suffered from MS for a long time said:

Participant: He [the doctor] feels you're more interested, you know, bothered to find out something about the condition and it saves him having to explain the basics. So I find I get more respect from doctors and nurses to... when you have information about the condition that you have,

Participants also regarded pre-consultation information seeking, and the understanding it provided, as useful in generally improving their relationship with their doctor. Some participants emphasised the value of information for enabling them to take on a more critical role. For example:

Participant: She [a relative who is a doctor] got some information together and lent me some books [...] before going to talk to the consultant, so when he came out with all those long words they weren't all completely new to me [...] so that I could ask intelligent questions when [...] he was giving his diagnosis... suggesting alternatives..

Researcher: So you could suggest alternatives?

Participant: Well, yes actually, up to a point. I could say well what about if this element of the condition changed? Would we then have other options? If we treat this first then can we take a different course of treatment later on? [...] Are there things that we can do first?

Where information seeking was motivated by a desire to critically evaluate diagnosis, the nature of the problem had already been established and this helped focus information seeking. Participants regarded the need to take a critical role as arising from a desire to identify the *best* solution for their particular circumstances, unconstrained by perceived limitations in the knowledge, judgement and priorities of the practitioner.

Participant: I wanted to survey all the options and not be limited to what was immediately available either locally or in the judgement of, initially, my general practitioner or the opinion of surgeon in the linked hospital.

and...

Researcher: So you were interested in exploring alternatives [yes]. Do you think that was something that the consultant, might not do automatically?

Participant: I wouldn't expect all of them to, but I'm also little bit cynical. [...] I mean there are consultants out there who have been doing this a certain length of time and they... they may want to follow a particular course of treatment because it makes them look statistically better at the end of the day, because they know they're going to get better results out of it, but it's not necessarily better in terms of long-term health for the patient.

As well as valuing information prior to clinical encounters, those encounters often triggered new information requirements, and hence further information seeking.

4.2 Seeking health information following a clinical encounter

Following a consultation in which a diagnosis was given, some participants reported information seeking motivated by a desire to better understand their condition or the condition of a relative, without necessarily having clearly specifiable questions.

Participant:... well, when I have been told that I have got erm... a certain condition, a certain illness whatever, erm... I have a son-in-law who has a stack of medical books, and I always go to those books to find out perhaps a bit more about my condition.

Having been diagnosed, some participants discussed wanting to know more about the prognosis of their illness: checking the diagnosis and treatment and seeking further information about how to manage the treatment.

4.2.1 Is the diagnosis right?

One motivation for post-diagnosis information seeking was the participant's need to ratify or clarify a diagnosis. This could centre on a diagnosis not conforming to illness experiences, diagnostic testing being regarded as inadequate or an overgeneralization of diagnostic categorisation, with poor discrimination between treatment options. For example:

Participant: I was looking for two things... I was looking for a confirmation through a description of the symptoms. And I was looking for erm... possible courses of treatment... how serious those treatments were and how effective they were likely to be, erm... So, mainly for treatment and confirmation through reading symptoms that that diagnosis was correct.

4.2.2 Is the treatment appropriate?

Following a proposed treatment, some participants sought information to obtain reassurance of the treatment choice and explore other, perhaps more beneficial, treatments. Others described seeking information to help them decide between known alternatives within the context of their own personal circumstances. For example:

Participant: ...I suppose for me the crucial decision was, erm... is there a good chance that I will REALLY benefit? Yes it will perhaps erm... inflict other difficulties on me and I've got to sort of be prepared for those. So, yes, it was viewing options for different procedures, but it was also I think for me at the time, working out a timetable as to whether I sort of er... jump into the operating theatre with both feet...

As in the extract above, potential side-effects were often cited as a factor in deciding whether a prescribed treatment was appropriate. Information seeking for alternative and perhaps more appropriate treatments, was sometimes prompted by: perceived limitations in health service budgets, a perceived inefficacy of the prescribed treatment, conflicting professional health information, or medically trained relatives questioning the treatment provided.

4.2.3 How do I manage my treatment?

Once a treatment had been prescribed, some participants expressed a desire to know more about how to manage their treatment. This included wanting to know how to administer the treatment properly. It could also include wanting to be aware of potential side-effects or complications, so that these could be anticipated and subsequently managed...

Participant: I mean one of the things with the beta-blockers was is dep.... a side effect is depression. And er... I was aware of this.

and...

Participant: Endometriosis I suspect it's a potential side effect from having done IVF. So I've researched that to make sure I know what to look for...

Other reasons for seeking information following a treatment prescription included investigating potential success rates and likely recovery times.

5. DISCUSSION

In this paper we have reported findings from a study into patients' information seeking, with a particular focus on their underlying motivations. The results show that information seeking can have a temporal element which relates critical events to the user's information journey. The results reveal information needs related to a key social event in healthcare, the clinical consultation.

Before a potential clinical encounter, participants described seeking information in order to assess whether they or a peer were in need of medical consultation. This was motivated by a concern not to waste National Health Service resources or their own time. They also described using available information resources to assess who might provide the best specialist help. Here they wanted knowledge to provide them with choices that were independent of what they would otherwise be offered.

The results also show that once a consultation had been arranged, many participants performed preparatory information seeking with two starkly contrasting yet complementary motivations. Firstly, participants explained that having background knowledge about conditions and treatments could allow them to contribute more usefully to the diagnostic and decision making processes and make better use of limited resources. Secondly, knowledge provided participants with the ability to ask for justifications behind a practitioner's proposals and to form their own independent opinions of the practitioner's judgements.

Following a consultation, motivations for information seeking included gaining a general understanding of a diagnosed condition, but also the more specific goal of ratifying or clarifying a diagnosis. Participants also described seeking information to decide for themselves whether a treatment was appropriate and to find out about any potential side-effects. Seeking out alternative treatments was prompted by the perception of budget limitations, inefficacy and conflicting advice. Finally, participants described seeking information in order to help them manage their treatment and, in particular, to recognize potential complications.

In assessing the need for consultation, patients described contacting NHS Direct for advice with respect to their circumstances, as well as seeking information to make that assessment themselves. Related to this, a number of participants discussed the value of knowing about potential conditions they might have in order to focus their doctor's attention to symptoms that might help them make a quicker diagnosis. Also, understanding the relationship between symptoms and conditions was seen as useful for managing treatment and recognizing side-effects.

In the media in recent years, concern has been expressed that the availability of health information on the Web is encouraging patients to self-diagnose. There is a worry, associated with the term ‘cyberchondria’ [e.g. 17], that patients can become unnecessarily worried and cause a drain on health service resources. Whilst the ‘worried well’ may be one effect of increased access to information, this study suggests the need to address a more complex reality. The participants in this study often referenced their information seeking against a desire to minimize demands on health resources. Information seeking was also frequently motivated by what they saw as limitations in available care which may or may not be justified. Participants’ information seeking behaviours were also found to be quite focused, rather than being a random search for possible conditions.

Furthermore, the participants identified information seeking on the Web as being key in correctly recognizing a physical phenomenon as a sign of serious illness, or reassuring them that it was not, thus avoiding unnecessary visits to a health professional. Moreover, these cases draw attention to a more general point: in order for an individual to recognise a need to access health services at all, they must first recognise the possibility that they are ill, and this frequently requires the interpretation of a physical symptom as indicative of illness. Such an interpretation requires constructing a plausible causal explanation, which itself requires general knowledge of the relationships between conditions and symptoms. Although false self-diagnosing may be a source of frustration for health practitioners, an informal diagnosis is frequently a necessary part of correctly recognizing that help is required.

On a more general theme, we have reported information needs as responsive to and structured around an evolving healthcare context within which clinical consultations provide significant reference points for the emergence of information needs. Six need related themes arose from the data which we expressed in the form of high-level questions: Am I ill? Who can help me? How can I prepare? Is the diagnosis right? Is the treatment appropriate? How do I manage my treatment? Whilst this list is certainly not exhaustive, it provides a basic framework for thinking about system design, and can be further developed through further research.

To conclude our discussion, and in the light of our findings, we return to an argument made in the introduction to this paper: that health digital libraries will be most accessible to patients if their design is deeply configured around patients’ situations, experiences and needs. Designers might apply the need-themes identified here as a checklist for reflecting on the intended scope of a system. Will a system, for example, help people locate specialists as well as inform about conditions? Are there further need-themes that the system should address, perhaps for a particular patient population? Beyond system requirements, the chosen themes might be reflected within digital library structuring, perhaps through theme-specific areas providing access to appropriately selected resources. This departure from traditional library structuring promises greater flexibility of resources to support changing patient needs through their ongoing experiences of illness. The need-themes identified can also act as a resource for formative and summative evaluation, using analytic or empirical techniques. Related to all of these activities, since the themes are derived from real situations, they can easily be used as a basis for generating realistic scenarios-of-use against which design and evaluation activities can be anchored.

Ultimately, this paper highlights the importance of contextualizing health digital libraries designed for patients’ use according to patients’ changing needs. Key to those patients’ changing needs, however, are significant real world events. Designing health digital libraries with those contextual events (e.g. doctor consultation, operation) in mind can help support effective patient interaction with those events.

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