

Information in practice

How the internet affects patients' experience of cancer: a qualitative study

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Abstract

Objective To explore how men and women with cancer talk about using the internet.

Design Qualitative study using semistructured interviews collected by maximum variation sampling.

Setting Respondents recruited throughout the United Kingdom during 2001-2.

Participants 175 men and women aged 19-83 years, with one of five cancers (prostate, testicular, breast, cervical, or bowel) diagnosed since 1992 and selected to include different stages of treatment and follow up.

Results Internet use, either directly or via friend or family, was widespread and reported by patients at all stages of cancer care, from early investigations to follow up after treatment. Patients used the internet to find second opinions, seek support and experiential information from other patients, interpret symptoms, seek information about tests and treatments, help interpret consultations, identify questions for doctors, make anonymous private inquiries, and raise awareness of the cancer. Patients also used it to check their doctors' advice covertly and to develop an expertise in their cancer. This expertise, reflecting familiarity with computer technology and medical terms, enabled patients to present a new type of "social fitness."

Conclusion Cancer patients used the internet for a wide range of information and support needs, many of which are unlikely to be met through conventional health care. Serious illness often undermines people's self image as a competent member of society. Cancer patients may use the internet to acquire expertise to display competence in the face of serious illness.

Introduction

The internet is changing the way that people learn about health and illness. Health sites and discussion lists are among the most popular resources on the web.¹ This increase in public access to health information has been welcomed but is often hedged with concerns.²⁻³ These include that the public may be prey to unscrupulous marketing, that public expectations may outstrip provision,⁴ the poor quality of much of the information, and the danger of an "inverse information law," whereby those who are in the greatest need of information about preventable or treatable conditions are least likely to have access to new technologies. However, others believe that wider access to medical information is inevitable and likely to encourage a balanced encounter between patient and health professional and to increase the appropriate use of medicine.⁵⁻⁶

Despite awareness of the potential impact of new information technologies on the roles and relationships of patients and doctors,⁷ little empirical research has been done on

how people with a serious illness diagnosed use information from the internet. In one of the few qualitative interview studies of internet use among people with a serious illness, Reeves showed why people with HIV infection or AIDS use the net: to seek help, make treatment decisions, research information, make social connections, and seek alternative therapies, and for advocacy, escape, and prevention.⁸ There are no comparable published studies of people with cancer, and data about their information needs are contradictory.⁹⁻¹⁰

We know little about what it means to patients to have access to health information on the internet, and the subject is well suited to qualitative inquiry.¹¹ We therefore explored how 175 men and women aged 18-83 with cancer diagnosed in the previous 10 years describe to what extent they used cancer information on the internet. We studied whether participants sought internet information about their cancer and how they perceived and used this information. We identify a broad range of uses and explore how the experience of cancer is being transformed for those with internet access.

Methods

Participants

The interviews we used were collected for research studies for the DIPEX charity, which runs a website (www.dipex.org) based on narrative interviews about people's experiences of health and illness. DIPEX aims and research methods are described in detail elsewhere¹² and on its website. In brief, for each disease module (such as prostate cancer or epilepsy) on the website, interviews are sought with the broadest practicable range of participants. This qualitative method is known as maximum variation sampling.¹³ Potential participants are invited to take part through their general practitioners, hospital consultants, support groups, and by word of mouth. A trained, experienced qualitative researcher from a social science background is responsible for collecting the 40-50 interviews that are usually necessary to ensure a sufficiently broad range of experiences.

Data collection

Participants are recruited at several different stages: after diagnosis, when undergoing treatment, shortly after treatment, and several years later. The researcher records a narrative interview in the respondent's home, or elsewhere if preferred. Participants are asked to tell their own story, from the point when they began to suspect there might be a problem. They are encouraged to tell their story in the way they prefer, with as little interruption as possible from the interviewer. At the end of the narrative, the interviewer uses a set of semistructured questions and prompts to explore particular issues further. Many respondents mention information sources in the narrative section of the interview, and

Reported use of the internet for cancer information and support in men and women interviewed for DIPEX studies and with cancer diagnosed since 1992

Site of cancer	No of respondents	Mean (range) age at interview (years)	No (%) of respondents with access to internet cancer information		
			Accessed by self	Accessed by friend or family	Total
Breast	37	44 (19-75)	17 (46)	2 (5)	19 (51)
Bowel	31	58 (33-80)	5 (16)	3 (10)	8 (26)
Cervix	21	40 (23-51)	6 (29)	4 (19)	10 (48)
Prostate	49	62 (51-83)	10 (20)	7 (14)	17 (35)
Testes	37	39 (21-55)	17 (46)	5 (14)	22 (59)

the semistructured section includes questions about how and why information and support has been accessed. Interviews are transcribed professionally, checked by the researcher, and returned to the respondent for change or approval before analysis.

For this study, we used DIPEX interviews with respondents who had had cancer diagnosed after 1992. We excluded respondents with cancer diagnosed before 1992 because internet use was then relatively unusual. The interviews included in this study were collected between January 2001 and November 2002. The table shows the distribution and age range of respondents. We analysed interviews for five different cancer groups: men with cancer of the prostate or testis, women with breast or cervical cancer, and 17 men and 14 women with bowel cancer. Consent procedures are approved by Eastern MREC (multicentre research ethics committee), and all interviews are copyrighted to DIPEX for use in research, teaching, and broadcasting.

Analysis

We read the interview transcripts repeatedly and coded them for analysis.¹⁴ We scrutinised each extract that described use of the internet for any purpose and then coded it under several anticipated themes (for example, decision making about treatment, information about the cancer) and emergent themes (such as guidance about how to talk to children about cancer, campaigning for wider recognition of symptoms). We used constant comparison in our analysis to ensure that the thematic analysis represented all perspectives.¹⁵ We also sought and discussed negative cases. We did not use significance tests to explore relationships within the data because maximum variation sampling was used for each of the five cancer types we analysed; this sampling procedure is designed to include the widest practical range of experiences, rather than to be numerically representative.¹⁶

Results

Why the internet?

The need for health information is not novel, but respondents with access to the internet talked about it having distinctive and appealing characteristics. These included privacy and 24 hour availability:

"So many people have computers nowadays, you haven't actually got to leave your house, it doesn't matter how you're feeling. You don't even have to get dressed; you can just, you know, log on and you can get the information. Which I think is going to do absolutely nothing but help people." (Man with bowel cancer)

Others noted that using the internet removes the embarrassment of face to face or telephone interactions. This feature seemed to appeal particularly to young men who might be worried about their health but reluctant to visit a doctor:

"It's so personal because ... it's your body, but you have to go somewhere. What better place to go than—well certainly in my circum-

stances, where I have a computer at home that I can switch on, in total privacy. I don't need to feel that I'm asking a dumb question. I don't need to feel that I have to ask all the right questions first time round." (Man with testicular cancer)

People may find it hard to predict when they will want to access different sorts of information about their health. With the internet, they can search for different types and levels of information as and when needed. The following excerpts show how the timing of people's need for information can differ greatly (see also quote by respondent TC07 in box 2):

"It's been helpful knowing where to look and being able to sort of follow the evidence and so on, but now I've reached the stage where I'm not looking any more. It kind of comes and goes; to begin with I wanted a whole lot of information, now I feel perhaps I don't want to know too much and I just want to try and keep going and not think too closely about what might happen." (56 year old woman with breast cancer, one year since diagnosis)

"I found I became very interested in it afterwards. Like, I'd say, after that first year. Like I started to want to ask different sort of questions and know what it looked like and that sort of thing; I was left thinking 'What was that thing?'" (33 year old woman, five years since diagnosis)

Who uses the internet?

The table shows how many participants in each of the five samples used the internet, either directly or via a friend or family member. Internet use was reported most often by men with testicular cancer and least often among the generally older patients with prostate or bowel cancer. Women with breast cancer were among the highest personal users of the internet, probably because many information and support resources for this disease are available on the internet.

The interviews did not explore the reasons why participants did not use the internet, but among such comments that were made the lack of home access and not being familiar with computers were the commonest reasons. A few respondents said that they thought they might be overwhelmed with information, were unconvinced that there is anything useful on the web, or—like the woman quoted above—were concerned that they might find out things that they preferred not to know. Some (particularly the older people) were keen to point out that they trusted their doctors and nurses to give them all the information they needed.

Reasons why the internet is used

Box 1 summarises a thematic analysis of the many ways people described using the internet throughout diagnosis, treatment, and long term and short term follow up. Participants in all five cancer studies talked about using the internet to understand the diagnosis, find information about treatments, learn about living with cancer, and gain support from others. The extracts in box 2 show how the internet was used to help patients express treatment preferences and supplement their consultations. Box 3 shows examples of use of the internet for social support, living with cancer, and campaigning to raise awareness.

How the internet is changing patients' experience of cancer

We identified two distinct ways in which respondents used the internet to transform roles and change involvement in health care—to covertly question their doctors' advice and to display themselves (to researchers, friends, family, and health professionals) as competent social actors despite serious illness.

Covert questioning

Patients described using the web to check up on their doctor's responses and advice at all stages, from the recognition of symptoms through recommendations for treatment and follow up.

Box 1: When and why cancer patients use the internet

Before visiting their doctor—To discover the possible meaning of symptoms

During investigations—To seek reassurance that the doctor is doing the right tests, to prepare for results, to improve the value of the consultation, to avoid *esprit d'escalier*

After the diagnosis—To gather information about the cancer (including information that is “difficult” to ask about directly), to seek advice about how to tell children, to contact online support groups, to seek second opinions, to make sense of the stages of the disease, to interpret what health professionals have said, to tackle isolation

When choosing treatments—Information about treatment options and side effects, experimental treatments, research, and alternative and complementary treatments

Before treatment—To find out what to take to hospital, what will happen, what it will be like, what to expect of recovery, how to identify and to prepare questions to ask the doctors

Short term follow up—Information about side effects, reassurance about symptoms, advice about diet, complementary treatments, advice on benefits and finances, to check that the treatment was optimal, perceived therapeutic benefits

Long term follow up—To share experience and advice, contact support groups and chat rooms, to campaign about the condition, to make anonymous inquiries

Sometimes they looked for information after being given contradictory advice or realising that their doctors found it hard to keep up with a rapidly changing subject. The internet also enables people to investigate the expertise and reputation of a hospital and staff and any evidence of “postcode rationing.” As the extract from respondent BC41 (box 2) shows, searches on the internet may be used after treatment for reassurance that optimal treatment was given. Other respondents identified treatments they preferred (PC42, CC19) and options that they suspected they would not have been offered (TC05). People differ in how they handle the information they have gained and how it affects their relationship with their doctors. However, the fact that this “checking up” can be achieved covertly without a doctor’s knowledge may avoid threats to “face” that could endanger the doctor-patient relationship and risk unnecessary conflict.^{17 18}

Displaying competence

Another way that the internet is changing people’s relationship with their illness is that they can gain, maintain, and display familiarity with a remarkable body of medical and experiential knowledge about their illness. Radley and Billig have pointed out that “being a good patient means having to fulfil a sociologically ambivalent position. The patient must appear to be more than a patient, a display of healthiness, or normality is also required for the individual to appear worthy of receiving the entitlements.”¹⁹

The ability to access a wide range of disparate information on the internet, coupled with the opportunity to present themselves as technically proficient and discriminating users of such information, enabled respondents to display a modern form of competence and social fitness in the face of serious illness. Indeed, the following quote suggests that there may almost be an obligation to seek information:

“We have one very big advantage ... and that is called the world wide web. Now I use Yahoo ... you go to Yahoo, and you type in testicular cancer, and I guarantee you that for the next two weeks you’ll be looking at every site that is different. You have people’s experiences, you have drug information, you’ll be able to read papers that are published on the web by some of the most eminent doctors around. There is no

excuse these days—if you haven’t got a computer go down to an internet cafe—there is no excuse whatsoever for not finding out about testicular cancer or all the other things... The information technology breakthrough of having the internet available is just unreal. You know, we’re very lucky because we’re at the dawn of something that is quite remarkable ... so there is really no excuse for not becoming totally aware of testicular cancer.” (50 year old man with testicular cancer diagnosed in 1992)

If competent patients seek information about their condition and question the treatment they have been offered does this imply that patients who do not do so are being negligent? Although this view was never stated in the interviews, the negative consequences of not doing one’s own research were regularly mentioned in the accounts. Examples in box 2 include respondent CRC16, who sought a second opinion when told that a stoma was inevitable and warned that doctors have neither the time nor expertise to be able to provide all the necessary information, and PC42, whose own research identified brachytherapy as the best treatment for his prostate cancer and who explained that specialist advice is too compartmentalised and unbalanced to help decision making. A young woman with cervical cancer (CC19) found an experimental cryopreservation treatment via the internet. Though she was aware that there was no guarantee this would work, she was keen to preserve her fertility and chose to go to another hospital for the treatment. TC29 pointed out that finding one’s own information can help one to plan for the consultation and identify appropriate questions, while lack of planning may result in suboptimum consultations and frustrating *esprit d'escalier* (“an apt retort or clever remark that comes to mind after the chance to make it has gone,” *Concise Oxford Dictionary*).

Concerns about the internet

Not everyone we interviewed who had accessed the internet described it as an unalloyed bounty. Several stressed the need to be wary or to check information by comparing it from different sources. No patients reported having been misled by inaccurate material themselves, which was probably evidence of distancing: in their accounts participants distanced themselves from other, less discriminating users of the internet (see BC33, box 3). Other participants explained that they preferred to avoid certain types of information—for example, cancer survival data:

“Um, only about two weeks ago was it the Audit Commission produced a document on patients’ cancers, so I had a look at that on the internet, and it gave the survival rates for different types of cancer—and for cervical cancer it is about 62%, something like 62%–64% which frankly came as a real shock to me ... The problem with finding out about cancer is you’re into medical statistics, statistics about death, and you don’t have the means of being able to cope with that. At least I didn’t.” (43 year old woman one year since diagnosis of cervical cancer)

Sometimes websites’ information was too all encompassing for British sensibilities, as suggested by this man with bowel cancer:

“The Americans, their websites, they give you everything. They tell you which prayer group to go to at the beginning and the end. They tell you which place to go on holiday, you know. They tell you which muffin to make life easier—you know, your constipation. And, uh, if you would like to dial and ring so-and-so they’ll tell you all about their situation.”

Discussion

This qualitative analysis of narrative interviews with people with a diagnosis of one of five different cancers not only shows the many different ways that people with cancer use the internet but also discusses the meanings that internet health information has for patients. We did not question respondents about why they did not use the internet, and so can say little on this issue. However,

Box 2: Expressed reasons why people with cancer used the internet for treatment decisions and to supplement medical consultations**Before the diagnosis**

"During that week I was looking at everything I could find on the subject, on the internet mostly ... I basically just put a search in on testicular cancer, and various sites and pieces of information came up ... it gives you some sort of comfort to know that certain types can be cured fully without too much of a problem, but on the other hand at that time I didn't know what sort of a problem there was. I mean, I didn't even know that it was testicular cancer, I mean it could have been anything." (TC07, man with testicular cancer diagnosed at 33 years old)

To research and prepare

"One can have a better knowledge of how to cope with such major surgery and trauma. I don't expect a surgeon to spend hours on end trying to describe what he was going to perform and what he was going to make your lifestyle after surgery. I think (the internet) is something which one needs to have access [to] because they are not going to be able to commit themselves to that length of time ... Sadly one has to do their own research. In every field of medicine there is an expert somewhere in the country, and they have to locate this person and have a consultation prior to surgery because the GPs don't have access to this information, and even if they do they are not going to spend two or three hours trying to phone round and find out who is the best surgeon ... I think a second opinion is something they need to do ... it's so important, so important." (CRC16, 52 year old man who survived bowel cancer without a colostomy after having sought a second opinion)

"The internet was invaluable the second time around when particularly we wanted information on primary cancer, you know, coming after another one, and the particular kind of cancer. I think they were very helpful, they give precise details of the cancers, and I felt that it was extremely helpful to get all the research and the findings and what they can do about it, the prognosis and all the rest of it—we did and friends did too. And I think it's very helpful the internet; when anything like that happens, I think that you can immediately go out and see what's going on, other than talking to doctors, and get statistics. I think everyone can be their own researcher now really; you can be in charge of your own affairs and know what's what. Nobody can pull the wool over your eyes." (BC12, 61 year old woman with ductal carcinoma in situ diagnosed in 2000)

When choosing treatments

"The problem with the options was that it was very, very compartmentalised. When I went to see the surgeon I think his idea was that radical prostatectomy is the thing, and that's what I heard from everybody else—because all urologists are basically surgeons, and they say 'To a hammer everything looks like a nail'—and I think that's very much the way it is." (PC42, 51 year old professional man who decided to have brachytherapy at a US clinic despite having been discouraged by the radiotherapist he saw in Britain)

"I didn't know a great deal about testicular prosthesis. I mean, I again looked in the internet, and there were a lot of American websites where people were talking about how difficult it was to get them in America because of silicone and all the scares that there had been, and that in this country at the time it was no particular issue. I don't know whether it's an issue now, but at the time it seemed to me that there was no compelling reason not to, and from what I knew about myself I'd probably feel a bit better about myself if I did have one ... I'm quite glad that it was an option. It was an issue I raised, it wasn't an issue that was raised by them, and I think if I hadn't said anything it wouldn't have arisen." (TC05, man with testicular cancer diagnosed at age 42)

"Basically my mum—because she's great and looking at all these internet sites, she read about having ovarian tissue, basically cryo-ovarian preservation, it's quite new. And so I had read about it, since my mum had found this information, and when I went to the hospital I discussed it with them. And actually they were a bit dismissive about it to be honest, and it certainly wasn't something they would have offered me had I not brought it up. And they said, 'Well, you can't have it done here, but you can have it done at another hospital.' So I phoned up the other hospital myself, made an appointment, and went in to go and see this woman, and she said to me, 'Yes, you can have it done.' And she said, 'There is, no children have been born as a result of this.' But what they do is they take out a portion of either one ovary or both ovaries, and this ovarian tissue is then frozen over a period of six hours by an embryologist and obviously stored in special little tanks." (CC19, woman with cervical cancer diagnosed at age 27)

To check that the treatment was optimal

"I've learnt an awful lot—er, maybe too much time on my hands, maybe not, I don't know—but I needed to know. Knowledge is power, and I needed to know that what was happening to me was the right thing ... I thought, with being in the UK, when reading about the therapies that the American people were having and the rest of it, I thought, 'Wow, what I've had is probably second best.' But it isn't. It's up there with the best, and I've had the best care that you could possibly imagine—the best surgeon, the best oncologist, the best breast nurse, ever." (BC41, 47 year old teacher with inflammatory breast cancer diagnosed, who set up her own website to increase awareness)

To supplement information from the hospital

"Of course, I asked the hospital for any information at all that they had that I could read up on and maybe take home, brochures and stuff like that, leaflets. So I took those home with me ... I got books and stuff from my local library and read it up again. And I have medical encyclopedias here, and we read up in those, and then of course on the internet. I went on to American sites and sought information. But it's the practical, uh, day to day dealing with this thing (the stoma) that has to, and making sure that it wasn't going to leak and I wasn't going to smell." (CRC35, 54 year old with bowel cancer)

To make sense of medical terms

"I was told I was booked for this 'radical hysterectomy'—which I hated the word, the radical bit, but then read on the internet that it's just the fact that they have to go to the outer limits, as far as they can go with regards to the hysterectomy. 'Radical,' it's just such a horrible word isn't it? It just sounds so absolutely dreadful and kind of drastic. And I got a little, she gave me a leaflet about cervical cancer and she said, 'You know that you're going to have to have a catheter and you'll probably go home with a catheter,' and at that point I didn't really know what that was or, you know, whether that was something in my stomach or how—but it's not through your urethra and bladder that way. But I didn't know that at the time, so I wanted to go looking on the internet, find out about hysterectomy, radical hysterectomy, how the incisions are done, and this catheter." (CC11, 23 year old student with cervical cancer)

To find the right questions to ask and avoid esprit d'escalier

"There is some information out there, and I think ... that for me one of the things that I needed to know most about was ... I needed somewhere I could go to that would say to me, 'Well, this is what the circumstance is. This is what's actually happened to you.' Um and yes, you can to a certain extent with a doctor, but there are never, you never ask the right questions at the time, um, you're just coming to terms with everything—you need time to consider that, and what better place to do that than at home and looking on the web?" (TC29, 42 year old company director with testicular cancer)

Box 3: Use of the internet for social support and living with cancer**To tackle isolation**

"I think that the worst thing about getting a diagnosis like this is a feeling of isolation, because you feel that your world has suddenly shrunk and all you can think about is yourself and you feel very frustrated because nobody has maybe experienced this. And when you're able to talk to other patients it's just very good to know that other people have been through this and to kind of share the experience with other people, and you feel much less isolated ... It's not just the medical information aspect, it's just a kind of support, moral support, which is very, very important when you've had a diagnosis of cancer." (PC42, 51 year old man with prostate cancer)

To find alternative and complementary treatments

"Quite a lot is written and discussed on the internet about alternative treatments, and if conventional treatments stopped working I would obviously examine some of those, but I don't need to at the moment, I'm delighted with how things are going." (CRC26, 57 year old man with bowel cancer)

To access experiential knowledge

"I mean a silly thing that I found out was that lots of cancer patients actually experience very, very bad mouth ulcers through the chemotherapy, because your body is at a very, very low ebb and unable to fight off all sorts of microbes or whatever which a normal fit person would fight off with no problem. You get ulcers in your mouth. Now one of the sites I found on the internet it said that one thing they recommend that cancer patients do is even after drinking a cup of tea have a mouth wash and brush your teeth after every meal—mouth wash and brush your teeth, which is what I did. And I didn't have mouth ulcers all the way through my chemotherapy, whereas other men going through the same chemotherapy regime as myself who didn't do that did have mouth ulcers. And that is something that the nurses on the cancer ward didn't even know about." (TC40, man with testicular cancer diagnosed at 27 years old)

Social connections

"I met a lady through an internet site for breast cancer survivors, which is an American site, although there are a lot of British women on there, and we were writing by email for two years, and I went out to see her in July—travelled to America with my husband, my children, er—and that's something that I wouldn't have done before, because we'd have put it off and put it off, and the money would have gone to something else. And it felt very important because we had the bond—we'd both had children, we were both in our 30s—and we did it, we went to America and met, and it was such an emotional meeting." (BC44, 34 year old woman with breast cancer diagnosed in 1997)

Perceived therapeutic benefits

"I got on to the internet, which is an amazing media, but it is also full of charlatans so you have to be extremely careful; it's a minefield. There are trillions and trillions of opportunities and people trying to sell you all sorts of cures, and I would say beware of that ... Get involved, be part of your own cure. It's really cathartic, it's, being involved takes your mind off the horror of it, and you immediately begin the process of fighting the disease." (BC33, 56 year old woman whose son gave her a crash course in using the internet after breast cancer was diagnosed)

To raise awareness about condition

[When asked if he would like to be able to talk about testicular cancer more openly] "Oh yeah, I've, that's why I've sort of started a website to try and spread the news. Er, I think nowadays it's probably, there's a lot more campaigns now to get to build up an awareness of testicular cancer ... the schools, football, schools, campaigns that are basically led by footballers that have got testicular cancer trying to spread the word. There's one or two, but you don't hear of many in the UK of actually people with the disease ... The only people I've found is searching on the internet where you see the news." (TC16, man with testicular cancer diagnosed at age 44)

lack of familiarity or of access were the main explanations people volunteered when asked if they had sought internet information.

Use of the internet by patients

Until recently articles in medical journals about the internet have focused on concerns about the quality of health information.² Some of our respondents voiced concerns about the difficulty of distinguishing between good and bad information on the web, but it is notable that they only expressed this concern for other, less wary people. In reporting their own internet use, they displayed considerable caution and competence and described techniques (such as comparing different information sources) to ensure that they were not misled.

The main contribution of this study is to show the many different ways in which the internet seems to be used by people with a serious illness, at all stages of their illness and follow up. We have also shown how patients' ability to become expert in their own condition may contribute to changes in relationships between patients and doctors. Patients who are concerned about the effects of cost constraints on health care (concerns that pre-date the widespread use of the internet) are able to use the web to seek reassurance about their treatment. Patients also want to know more about complementary approaches to treatment, but, as others have shown, may be anxious not to jeopardise their relationship with their doctors by revealing their interest in self treatment.^{20 21} As Jadad and colleagues recently suggested, "It will

take time and effort to reach the point where the assertive patient is recognised as the 'good' one. Ignorance, fear, inertia, and stubbornness remain to be overcome."¹⁸ The desire to canvass an informal (and therefore face saving) second opinion will be familiar to all who have ever sought supplementary information for friends and family faced with treatment decisions. The internet extends this ability to those whose social circle does not include medical professionals (and probably makes the process more reliable for those whose social circle does include medical professionals).

The internet extends the scope of the best stocked medical library, through access to experiential knowledge as well as medical information. Health professionals in training as well as patients stand to benefit from this, but as yet the internet is rarely used by people who are socially disadvantaged. Unequal access to the internet may increase social class divisions in health care, but this is not inevitable. Indeed, in one UK study socially deprived respondents said they were more inclined to use the internet than more prosperous ones,²² and in a US study African-Americans reported higher use of the web for health information than the general population.²³ On reflection, it is not surprising that such resources have particular appeal to those who suspect (rightly or wrongly) that their ethnicity, age, education, social class, or income may militate against an equal and honest relationship with their doctors.²⁴ The challenge is to

What is already known on this topic

The internet is a fast growing source of health information and support for patients

There has been little research on how people with a serious illness use the internet, or how this use may change their relationships with clinicians

What this study adds

People with cancer reported using the internet for a wide range of information and support needs at many different stages of their illness

Access to the internet allows people to check covertly the tests, treatment, and advice they receive from health professionals

People who access the internet to gain expertise about their condition can use this to show that they remain competent members of society despite serious illness

ensure that access is broadened through appropriate, supported public channels such as cancer information centres and public libraries.

Limitations of study

The interviews used in our analysis were collected for five individual projects for the DIPEX database, using the same interview methods and maximum variation sampling. The samples should not (individually or together) be interpreted as numerically representative of cancer patients, having been selected to represent the broadest practicable range of experience, as is appropriate to the aims of this qualitative study.

Many important questions about the impact of the internet are beyond the scope of a qualitative interview study. These include what impact the internet has on the consultation, how it affects patients' participation in decisions, what effect it has on health outcomes, and, indeed, what the relevant outcomes are. This study prepares the ground for further qualitative and quantitative work by identifying the many different ways and stages at which information on the internet is used, as well as the meanings the internet has for patients and the implications for relationships in health care.

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