THE BRITISH PAIN SOCIETY

The role of the Internet for people with chronic pain: examples from the DIPEX International Project

British Journal of Pain
2015, Vol. 9(1) 62–64
© The British Pain Society 2014
Reprints and permissions:
sagepub.co.uk/
journalsPermissions.nav
DOI: 10.1177/2049463714555438
bjp.sagepub.com

Sue Ziebland¹, Maya Lavie-Ajayi² and Gabriele Lucius-Hoene³

Abstract

In this article we consider how people with chronic illness are using the internet, drawing on examples from published qualitative interview studies of experiences of chronic pain in the UK, Germany and Israel. Extracts from the interviews can be seen on the websites from the www.dipexinternational.org collaboration which publishes analyses and many thousands of video and audio interview clips on country specific web platforms. The UK branch of the collaboration has been operating for over a decade and currently includes broad based samples of qualitative interviews with patients about their experiences of over 80 health problems.

The research has demonstrated that people living with chronic pain are increasingly using the web to find information, support and practical advice for self-management and also for reassurance, encouragement, to compare experiences of treatment and to offer advice and support to others. The internet is changing the way that people are experiencing illness, although access to relevant and reliable online material is not equally distributed. Those who do not speak one of the handful of dominant languages are less likely to find online experiences that resonate with their own.

Keywords

Chronic pain, pain, pain management, internet, pain perception

People facing similar health issues have always learned from and supported each other: in recent years, Internet platforms with personal experiences, patient blogs and forums have radically enhanced people's ability to make these contacts, no matter where they are, how rare their condition or what time of day or night they are searching. In this article, we consider the role of the Internet for patients, drawing on the example of the DIPEX International projects with people with chronic pain in Israel, Germany and the United Kingdom.

In our highly efficient, technical and institutionalised procedures and systems of providing healthcare, the subjective side of living with illness can seem to take a back seat. Even in a biopsychosocial model of disease, clinical practice and research often position people's knowledge about their own health and their perceptions of the impact of medical diagnostic and

treatment processes as secondary to scientific scrutiny, quantification and top-down research procedures. In contrast, narrative approaches see the 'voice of the patient' as an important and irreducible perspective in its own right as well as providing highly evocative,

¹Nuffield Department of Primary Care Health Sciences, University of Oxford, Oxford, UK

²The Spitzer Department of Social Work, Israeli Center for Qualitative Research of People and Societies, Ben-Gurion University of the Negev, Be'er Sheva, Israel

³Department of Rehabilitation Psychology and Psychotherapy, Institute of Psychology, University of Freiburg, Freiburg, Germany

Corresponding author:

Sue Ziebland, Nuffield Department of Primary Care Health Sciences, University of Oxford, Gibson Building, Radcliffe Observatory Quarter, Oxford, OX2 6GG, UK.
Email: sue.ziebland@phc.ox.ac.uk

epistemologically rich and helpful evidence for research and service improvement.

The DIPEX International project (<http://www.dipexinternational.org>) is part of this new movement: a collaboration of qualitative health researchers who conduct interview studies for ethically funded, easily accessible websites which present analyses and hundreds of video and audio interview extracts. The studies use open-ended, in-depth interviews and maximum variation, nationwide sampling to ensure that each condition-specific collection includes a broad range of experiences.¹ Transcripts of interviews are analysed with rigorous qualitative research methods to ensure that authentic and varied insights from patients' experiences are presented online for other patients, relatives, the public, health professionals in training and policy makers.² Interview participants are invited to review the transcripts of their interviews and remove any sections that they do not wish to be used on the website or in research. The participant then has the option of selecting the video, audio or anonymous, written version of the interview to be copyrighted to the host university for teaching, research, secondary analysis and broadcasting. The transcripts are archived and available under licence to other academic research teams for specific, non-commercial purposes.

The national teams which build DIPEX collections collaborate and share their procedures and data for cross-cultural research on illness experiences and the impact of national health systems on the level of the individual patient.³

Research on the pain data has also focussed on how patients make use of healthcare institutions and treatment, identify options and maintain their own agency in the face of debilitating pain. We have conducted comparable studies of experiences of chronic pain in the United Kingdom, Germany⁴ and Israel⁵ – participants discussed bodily changes, the frustration of having an 'invisible' condition,⁶ consequences for relationships, work and identity as well as experiences of consulting, diagnosis and various types of treatment. Participants told us they were using the web to find information, support, practical advice for self-management, reassurance, encouragement, to compare experiences of treatment and offer their own advice and support to others.

Use of the Internet by people with chronic pain

Extracts from the UK study shed some light on the role that the Internet plays for people with chronic pain.⁷ It is increasingly common for people to search the Internet as soon as they become aware of symptoms or as soon as they become aware of a searchable label for their condition:

[the website] covered such topics as the pain clinic, pain and depression other subjects on pain and the management of pain [...] it was an amalgamation of a lot of research that's been done from those accredited books, but it's something that is very readable and quickly understandable, and extremely relevant.

I could liken myself to a lot of the symptoms that were being expressed in the research [...] Similarly with the pain and depression page, the Amitriptyline was explained as it should have been explained before that, you know, by my GP, and I would say my chemist as well.

People who were able to make contact with others and learn from their experiences in managing pain emphasised the benefits of peer support. A woman whose chronic pain has started some years ago felt that she was seen as a 'classic heart sink patient' with a depressingly thick case file. She felt that she needed to find an explanation for her pain, and since it was 'well before the internet ... it was quite difficult to get access to medical journals and the sort of information I wanted'. Like many others we have talked to, she also found it 'enormously helpful' to make contact, through a support group, with others with chronic pain: 'we all had different stories and we all had different conditions [...] and we formed a very supportive group which I found because at last I could talk to people who understood where I was coming from'.

Another woman with chronic pain pointed out the value of Internet support for people who are socially isolated due to disability:

the other good thing about the internet is the fact that you meet, and especially for people who are really disabled and can't get out, is that you can have a circle of friends, you know, and talk to people. I mean, if you have a look into some of these forums sort of things, people are just talking about ordinary, everyday sort of things, like things in their back garden, you know, flowers and stuff and I suppose, for some people, that it opens up a new world to them.

People also voiced several cautions which were particularly aimed at those who might be taken advantage of by unscrupulous commercial interests. A man with back pain said that he had become a bit disillusioned with finding so much 'American' and 'Drug company' sponsored material. He emphasised the variability of experience in chronic pain:

I am convinced that (chronic pain) is one of those things you can't really generalise about. I mean if I were to put anything on the internet I would say that pain doesn't mean the same thing to two different people. And if it is going to be constant in your life, you, the sooner you can (a) come to terms with that and (b) find ways of dealing with it, the happier you are going to be and the quicker you are going to be happier as well.

Countries within DIPEX International collaboration are conducting evaluations to explore the potential effects (positive and negative) of accessing other people's health experiences online. Underpinning this work, a conceptual literature review⁸ identified seven potential domains: finding information, feeling supported, maintaining relationships, affecting behaviour, experiencing health services, learning to tell the story and visualising disease. Each domain has the potential for both a positive and negative effect and can be assessed with the e-Health Impact Questionnaire studies. A current National Institute of Health Research (NIHR) programme grant for applied research incorporates exploratory, experimental and feasible mixed-methods research to explore how people use and respond to online patients experiences. The final projects will be reporting in 2015 (see <http://www.ipexonline.org> for information about this programme).

The UK site <http://www.healthtalk.org> is the most established site in DIPEX International: in June 2014, the site received 176,224 individual visitors. These visitors watched 43,975 videos, more than half of which were watched all the way through. Site visitors are mainly (two-thirds) using the site in relation to their own health issues, while 25% are looking for friends and family. In response to brief online questions, 93% of respondents said they would recommend the website and 85% of respondents found the information on the site more useful than elsewhere.

Unequal access to the Internet

People's online accounts of their experiences (whether in blogs, chat rooms or research-based sites) may help others to live with their illness and use their personal, social healthcare resources more effectively.⁸ Yet, while the Internet is a global resource, there are still great disparities in access and use of information and communication technologies, within countries⁹ and between countries.¹⁰ Web resources, particularly those featuring patients' experiences, are produced in a relatively small number of wealthy countries and tend to represent the least disadvantaged. English speakers have access to many more web resources than any other language group. People from marginalised communities in developed countries and those in low- and middle-income countries, even if they have access to the Internet, may find it hard to locate online patients' experiences that resemble their own. Differences include health and payment systems, cultural perceptions, attitudes and practices as well as language. In our studies, patients from marginalised communities in Israel discussed feeling isolated while using local web patients' forums. They could not find many online patients' accounts in their language. Their experiences were not reflected in the online discussions because of cultural differences. When they used international web-based forums in

their own language they faced other problems if they did not share the same healthcare system or opportunities to meet face to face (some on-line forums complement off-line activities that offer opportunities to meet other patients face-to-face, and specialist lectures).

The Internet presents remarkable opportunities to transform the experience of chronic pain and other health conditions by drawing on people's willingness to share their experiences online. Language and access are important considerations, but we suggest that the international community also needs to attend to disparities in relevance. One way to do this would be to help produce locally led, culturally appropriate projects to produce e-health resources in developing countries and from marginalised communities in developed countries.

Declaration of Conflicting Interests

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The authors received no financial support for the research, authorship, and/or publication of this article.

References

1. Pope C, Ziebland S and Mays N. Qualitative research in health care: analysing qualitative data. *BMJ* 2000; 320: 114–116.
2. Ziebland S and McPherson A. Making sense of qualitative data analysis: an introduction with illustrations from DIPEX (personal experiences of health and illness). *Med Educ* 2006; 40: 405–414.
3. Ziebland S and Kokanovic R. Emotions and chronic illness. *Chronic Illn* 2012; 8: 159–162.
4. Lucius-Hoene G, Thiele U, Breuning M, et al. Doctors' voices in patients' narratives: coping with emotions in storytelling. *Chronic Illn* 2012; 8: 163–175.
5. Lavie-Ajayi M, Almog N and Krumer-Nevo M. Chronic pain as a narratological distress: a phenomenological study. *Chronic Illn* 2012; 8: 192–200.
6. Dow CM, Roche PA and Ziebland S. Talk of frustration in the narratives of people with chronic pain. *Chronic Illn* 2012; 8: 176–191.
7. <http://www.healthtalk.org/peoples-experiences/chronic-health-issues/chronic-pain>
8. Ziebland S and Wyke S. Health and illness in a connected world: how might sharing experiences on the Internet affect people's health? *Milbank Q* 2012; 90: 219–249.
9. US Department of Commerce, National Telecommunications and Information Administration (NTIA). Falling through the net: a survey of the 'have nots' in rural and urban America, 1995, <http://www.ntia.doc.gov/ntia-home/fallingthru.html>
10. Chinn MD and Fairlie RW. *The determinants of the global digital divide: a cross-country analysis of computer and Internet penetration*. Economic Growth Center, 2004, http://www.econ.yale.edu/growth_pdf/cdp881.pdf