Hear and see people talk about their experiences of health and illness

The HealthTalkonline website http://www.healthtalkonline.org/

Healthtalkonline documents the experiences of health and illness of over 2000 people. It is based on research from the Health Experiences Research Group at the University of Oxford. The website is run by the DIPEx Charity and was previously known as www.dipex.org. It includes videos and transcripts of interviews with people living with over 40 health conditions as well as interviews with carers of people living with health conditions. There are also links to other resources such as overviews by experts and information designed for health care consumers. Many of the featured conditions or settings are of direct relevance to physiotherapists. Chronic pain, diabetes, breast cancer, lung cancer, stroke, motor neurone disease, Parkinson's disease, congenital heart disease, rheumatoid arthritis, osteoporosis, pain during pregnancy, and the experience of being a patient in an intensive care unit are all covered by the website.

This is an impressive website. The links to videos of people talking about a range of aspects of health and healthcare would be of use to those affected by these conditions, family members and friends of those with health conditions, and health professionals. This would be an extremely useful tool for those seeking to encourage physiotherapy students or graduates to better consider patients’ experiences.

The website claims to provide ‘reliable information about conditions, treatment choices and support’. However, it focuses more on the experience of illness than on evidence-based care of the illnesses. The information about the experience of illness and different treatment options is excellent. Consumers can obtain evidence about the effectiveness of interventions from other sources such as the consumer summaries on the Cochrane Library. Information written for consumers about the effectiveness of physiotherapy interventions can be found at the Physiotherapy Choices website (http://www.physiotherapychoices.org.au/).

Healthtalkonline is well laid out and easy to use. One can look for a health condition of interest via multi-coloured left menu bars, an alphabetical list of conditions, or a search box. Some health conditions have multiple video interviews and other resources. Other categories did not include much material. For example the section called ‘later life’ had only one topic area: sleep problems in later life. However the website states that it is a work in progress with more health conditions being added as research is completed. The aim is to cover over 100 health conditions in the next 5–10 years. Some pages seemed a little slow to load. I think usability would be further improved by having a ‘transcript only’ option so one could read through interview transcripts without watching videos. This would be quicker for the user and may be particularly important for those with slow internet connections or download limits. Having said this, for those with adequate internet connections the videos are an excellent feature as one gets a much better ‘feel’ for the individuals’ experiences from non-verbal aspects which would not be apparent in a written document.

The website also has a forum section which enables people affected by health conditions to post messages about their experiences. This feature does not seem to be heavily used at present. There was an indication of ‘lurking’ as some posts had been read over one thousand times but had not been responded to. This feature could be useful in the future. Many people affected by health conditions enjoy online discussion with others affected by the same condition. The internet is a fantastic resource for this as it provides a discussion forum for patients or carers who are physically, geographically, or logistically unable to attend an in-person support group. It also caters for those who are reluctant or unwilling to attend a face-to-face meeting. It also increases the likelihood of people affected by rare conditions to be in touch with others affected by the same condition. Of course, aspects of internet security and safety need to be observed as one cannot be entirely sure who one is ‘speaking’ to online.

The news section of the website also seemed to be under development. It encouraged the user to ‘read our press releases’ but did not list any.

The site has a clear help section and detailed information about the people behind the website. There is a list of funders and a link to the funding policy which states that money will not be accepted from pharmaceutical companies or any for-profit organisation with vested interests in the research findings.

In summary, this is a very useful website and I encourage readers to visit it and to consider recommending it to colleagues, students, and computer-literate patients.

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