

Note.

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Review: The experience of chronic illness among a group of Irish patients: a qualitative study

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It is always refreshing to read a paper that focuses on peoples' experience of 'living with' rather than focusing on the their self management, or adherence to treatment regimes, as it enables a 360o view of the issues for the patient that underpin their approach to health care professionals.

This was a small-scale study, which is acknowledged by the authors. It does however reflect similar findings in other studies; that people living with a long-term condition experience a sense of loss, feelings of anger; frustration and stress. The overwhelming feeling I was left with after reading the paper was of negativity, struggle and loss. One finding was of social isolation, and the authors suggest that social groups and clubs should be set up 'to help them socialise and support each other'. Whilst the internet and social media are not the solution to every problem (or right for every person) there are excellent online groups, quite often condition specific, where people discuss many of the issues the authors identify. This form of peer support should not be overlooked.

One theme that emerged was that of 'adopting a positive outlook on life with chronic illness'. It seemed however to be lost under the weight of accurately reporting the challenges that participants faced. I do wonder if different conditions generate different experiences, something the scale of this study could not capture. As Wilson (2011) highlights, trying to capture complex experiences is a challenge to researchers and often the full essence of the experience is missed. Patient accounts of their experience when not participating in structured research often mention the same frustrations and issues for people as researchers find. Davis (2006) talks about 'road rage' and being 'in the eye of the storm'. Miserandino (2010) gives a painfully realistic description of living with Lupus in her 'Spoon Theory'. Colin, a participant in The 'Diabetes Stories' project (OCDEM undated) discusses his various health problems and then says 'can't moan about it, so I just really, daft as it sounds, enjoys life. It's as simple as that'.

The experience discussed by individuals outside of a research framework is greater than the sum of the component parts. Whilst there are negative aspects, and certainly things that health services could start doing, or indeed stop doing, that would be of great benefit, many of the individual accounts available do not focus on the negativity of the lived experience. In spite of the challenges they do not report of 'suffering' with a chronic condition.

Good researchers always endeavour to fully and accurately reflect the findings of their research, and it is not up to them to decide which aspects of their participant's experience dominates if the research does not make that clear. As social media brings us more unfiltered accounts of people's experiences, such as through online discussion boards, we need to explore new ways of capturing and understanding those experiences that does not risk reducing experiences to the component elements.

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