Emotions and chronic illness

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The experience of chronic illness is often emotionally challenging. People respond to these challenges in very different ways yet their responses are inevitably shaped by their resources and social position, the wider environment and clinical, personal and societal reactions to their symptoms and diagnosis (or lack of diagnosis). This special issue of Chronic Illness features six papers, which all consider how people experiencing chronic illness talk about, and live with, emotions in different cultural contexts.

We include papers from researchers in four countries: Japan, Israel, Germany and the UK. All of the researchers are members of the DIPEx International (DI) collaboration of qualitative health researchers and health professionals who have been inspired by the UK project, which produces www.healthtalkonline.org and www.youthhealthtalk.org. The first UK collections were published in 2001 and now include over 70 different health and illness sections. Similar studies have been conducted for sister websites in Australia, Japan, Korea, Spain and Germany. Projects are underway in the Netherlands, Israel and Canada and planned in many other countries.

All of the DI projects use the same qualitative research methods: each collection involves a diverse, maximum variation sample of interviews, collected and analysed by experienced academic social scientists. Researchers travel throughout their country conducting digital video or audio (depending on the participant’s preference) recorded interviews with between 40 and 50 participants. People are interviewed at a place of their choice, usually their home; we avoid clinical settings. The interviews share a similar structure. First, the researcher invites the participant to tell the story of what has happened since, for example, they first suspected a problem. When the respondent indicates that this, the ‘narrative section’, is complete (in our experience this might take anything from 5 min to 5 h) the researcher uses prompts and questions in a semi-structured section of the interview. Sometimes more than one interview is needed. The narrative section of the interview is intended to provide a space for the participant to tell their story and to identify the participants’ own priorities, rather than to elicit responses to a more narrowly focussed agenda. Cultural variations in responses to this kind of interview are likely but, while the research interview is arguably a western construction, storytelling is a feature of all human societies.

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A transcript (or recording, if preferred) of the interview is sent to the participant for comments and approval. Before the researcher starts the formal analysis each participant signs a copyright form giving permission for their interview to be used for a variety of purposes including research, teaching, publication and on the websites.

The content of the website is prepared by the researcher, supported by a qualitative research 'buddy' and team of specialist advisors, including service users. Thematic analysis is used to identify and explore a combination of anticipated and emergent themes from the interviews. Around 25 of the key topics (such as early signs and symptoms, deciding to see a doctor, diagnosis, experiences with health system, treatment decisions, finding support and information) are written up to incorporate all perspectives in the dataset. Interview extracts are chosen to illustrate these thematic summaries which, with biographies of the participants, and around 250 video, audio and written extracts carefully selected from the interviews, are then entered into a website similar to www.healthtalkonline.org but with culturally context specific variations of design and presentation. See www.dipex-j.org, www.healthstory4U.co.kr, www.dipex.es, www.krankheitserfahren.de and www.healthtalkonline.org/mental_health/Experiences_of_depression_and_recovery_in_Australia for the Japanese, Korean, Spanish, German and Australian collections.

In September 2011 DI met at the Monash University Prato Centre (Italy) as guests of Monash University. Researchers held a two day workshop to present and discuss papers on emotions and chronic illness, drafts of which had already been submitted internally to DI academic members for comments. The workshop was a great success: everyone had used a similar approach to collecting interviews and thoroughly enjoyed hearing about and discussing papers with fellow DI researchers. We were intrigued by the parallels and contrasts between experiences of chronic illness in different cultural settings.

While everyone in DI uses qualitative thematic analysis to prepare material for their websites, this collection of papers shows that the interviews provide rich data for a number of other analytical approaches, including socio-linguistic analysis, an interpretative phenomenological analysis (IPA) and an exploration of metaphors in accounts of living with Motor Neurone Disease, as well as thematic analyses that draw on how people talk as well as what they say. Also, although all of the studies drew on projects with similar numbers of interviews the analyses featured in this special edition focus on data sets that range from six narratives to 394 narrated scenes extracted from 56 interviews.

Focussing on emotional experiences of living with a chronic condition, the papers in this collection feature studies with people experiencing chronic pain in the UK, Germany and Israel; experiences of breast and prostate cancer in Japan; diabetes in Germany; Motor Neurone Disease (MND) in the UK and young people living with epilepsy in the UK.

The experiences of chronic pain in the UK, Germany and Israel bear considerable similarities, emphasising the challenge of living with an illness that is both ‘invisible’ and difficult to treat. Lucius-Hoene et al. explore patients’ accounts of their interactions with doctors, focusing on positioning and narrative analysis. They show the impact of the underlying moral problems which illness can introduce into the doctor–patient relationship. Dow et al. consider the expression of frustration in interviews and conclude that frustration coalesces around the invisibility and the difficulties of treating the condition. Six chronic pain narratives analysed from an Israeli study again underline frustrations and focus on the threats to both the patient–doctor relationship and self
understanding. Dow et al. conclude that doctors may have more effective consultations with chronic pain patients if they acknowledge (perhaps repeatedly) the frustrations inherent in living with an invisible, debilitating condition. These similarities are particularly intriguing because the health and benefits system in Israel does not recognise chronic pain patients as having a medical disability and thus excludes them from benefits under the National Insurance scheme. Yet these papers demonstrate that chronic pain is a compromising condition in all three countries, suggesting that the problem relates more to the social legitimacy of the condition and its effect on clinical and personal relationships, than any relationship to the benefits system.

Both Lucius-Hoene and Locock et al. look closely at the language that people use in their narratives. While Lucius-Hoene considers how people living with diabetes and chronic pain position their doctors’ voices in their accounts, Locock and colleagues explore the use of metaphors to convey emotions in interviews with 46 people affected by Motor Neurone Disease (MND). MND is a progressive neurological condition that lies between chronic and terminal illness and it is striking that compared to analysis of cancer narratives, people with MND are considerably less likely to use metaphors of ‘fight’ and ‘battle’. Emotional states are often conveyed in metaphorical language; the authors conclude that sensitivity to metaphors may help health professionals to communicate with people affected by MND.

Raisanen and Ryan interviewed young people (aged between 16 and 28 years) experiencing epilepsy. Epileptic seizures provoked a particular fear. Because seizures involve the brain (the ‘cradle of the self’) they threaten to compromise who the young person is and who they might become. In this way epilepsy may differ from other (potentially life threatening) chronic conditions, such as asthma. Emotional responses in epilepsy may be more similar to those experienced by people living with dementia, or people who have had a stroke or another neurological condition.

The Japanese group draw on their interviews with men with prostate cancer and women with breast cancer to explore preferences and emotional reactions to the prognosis regarding survival. Sato et al. consider the reasons why people do, and do not, want to be told by doctors about their prognosis and discuss their reactions to how this information (often about ‘survival rates’) was conveyed by doctors. Their analysis indicates an absence of mutual shared understanding about the value of prognostic information regarding survival and how it might be used by patients to inform treatment choices. This may explain why surveys show that only between a fifth and a third of cancer patients in Japan are given their survival prognosis.

Clinical evidence about the effects of interventions, treatments, medical devices and approaches to disease management are expected to apply globally, allowing for the evident differences in health systems and an individual’s health insurance status. The DI collaboration was prompted by our conviction that, even if future generations of language translation tools become suitably nuanced (and thus less unintentionally hilarious …) the experience of illness diverges in different societies. The DI collaboration offers the opportunity to compare in-depth illness narratives on an expanding range of health issues (e.g. three countries have now studied diabetes, more will follow) and cross-topic issues including interpretation of symptoms, communication with health professionals, managing medicines, and telling friends and family about the diagnosis. We are interested in these questions (and many more) and hope that others will join the collaboration to help us share and compare data, learn from the findings and
use them to make a difference to the experience of chronic illness.

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References


