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Project Title:

Accounting for Chronic Fatigue: patient narratives and professional perspectives

The Health Communication Research Centre (HCRC), as an interdisciplinary initiative within Cardiff University, co-ordinates communication and discourse based research in areas of health and social care. This project in narratives of chronic fatigue is funded by The National Assembly for Wales (WORD) under their Responsive Research Scheme.

Patient accounts of chronic fatigue syndrome (CFS) are the basic resource available to clinicians in managing this condition. Often the constraints of the clinical encounter make difficulties for both patient and doctor, where the telling of the patient's story is secondary to the process of diagnosis and prescription. Because of the sensitive and controversial status of CFS, patients often consider themselves to be judged pejoratively, even to the extent of being viewed as malingerers. Furthermore, there is at present a climate in which competing versions, or discourses upon the illness, are presented by physicians, by psychologists, by the media, and by patients themselves. By recording and analysing a substantial number of open-ended interviews with patients, supplemented by both clinical interactions and interviews with practitioners, we hope to provide an invaluable resource for professional practice, assist in patient awareness of their own condition, and suggest ways in which doctors can re-assess the management procedures for CFS.

The principal aim of the current research is to achieve a greater and more detailed understanding of Chronic Fatigue Syndrome by means of a study that would encompass (a) patients' narrative accounts of their illness experience; (b) recorded data from patient encounters with medical professionals; and (c) interviews with those and other medical professionals. With these three sources of spoken data, we would be in a position to provide an overview of the condition as well as specific interactional accounts of the entire unfolding process of illness representation both in the clinic and outside it.

We are interested, specifically, in the following questions:

- Agency and causality: what events, symptoms and processes are construed as causing the illness or its identified effects? Where and how is blame attributed?
- Representations of control and passivity: do patients portray themselves as being in control of their conditions and lifestyles in CFS - which, how and to what extent?
- Self and identity: do patients represent themselves as being, in some senses, different people in CFS from previously? Along which dimensions, and how are these attested?
- Social trajectories: how, in terms of narratives of change, do patients represent their future identities and relationships relative to CFS?
- Does the discursive representation of symptoms and illness experience differ noticeably and consistently in the non-clinical setting from the clinical, and if so, what can be learnt from these differences?
- What accounts and explanations are given by medical professionals in the management and care of CFS patients, and how do they differ from those of the patients themselves?

It is believed that the different communication processes required by the clinical consultation and the informal interview will provide distinct modes for assessing the process of *narration*, that is, the description of actions and events which gives order and coherence to patients' experience of CFS.

Period of Research: 1 November 2001 - 31 October 2004

Project team: Dr Richard Gwyn (project convenor); Dr Bernard Nolan (Research Associate); Dr Meirion Llewelyn (consultant physician); Dr Lindsay Prior (SOCSCI, Cardiff University); Professor Leszek Borysiewicz (Principal, Imperial College of Medicine, London).

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