Narrative research in health and illness

Readers versed in literary theory – and I cannot be the only one – may find the title and contents of this book daunting. Its division into three sections, ‘Narratives’, ‘Counter-narratives’ and ‘Meta-narratives’ is not comforting. Be not afraid. Although many of the contributors write within a conceptual framework that is unfamiliar, use language that is taxing and occasionally obscure, and frequently challenge the tenets of conventional medicine, all succeed in revealing dimensions of human interaction that are elusive and usually unapparent in traditional medical encounters.

Narration, or story telling, is such a natural and universal commodity that its close academic scrutiny might seem superfluous. Not so: it has been a preoccupation of philosophers, philologists, psychoanalysts, literary theorists and others from Aristotle to Derrida. It has generated a vast literature and, at times, a barbarous psychoanalysis, and frequently challenge the tenets of conventional medicine, all succeed in revealing dimensions of human interaction that are elusive and usually unapparent in traditional medical encounters.

Although there is great diversity in theoretical approaches to narrative, and variation in the extent to which contributors to this book engage with them, the direction and meaning of narrative research within the context of each of its chapters is self-evident. The authors come from a wide variety of academic backgrounds and readers need not be distracted by the interpretive ambiguities that arise. An essential theme of most of the 23 chapters is that there are layers of meaning in stories of illness and suffering that are not revealed in conventional interviews; that whilst we emphasise the importance of communication and the centrality of patients’ histories, we do so within the framework of an institutionalised biomedical model. It is suggested that doctors’ accounts of illness are shaped by a different narrative logic from that of patients; that patients’ experiences are reconstructed by doctors and the patients’ subjectivity lost. The extent to which contributors see the narrative-based approach to research as conflicting with rather than complementing the evidence-based approach varies, but all believe that the uniqueness of personal experience is lost in the generalities of biological structures and mechanisms and that a statistically constructed population is bereft of the feelings and emotions of the men and women that comprise it.

The topicality of the issues on which many of the contributions are based adds to the appeal of the book. A chapter in the first section relates to the SARS epidemic in Hong Kong in 2003. It includes extracts from two articles published in the Lancet, both written in the conventional language of medical reporting. Eugene Wu, a co-author of one of them and a young doctor of ten years experience, was amongst several front-line health care staff who fell victim to the disease. He survived but witnessed from his hospital bed the suffering and death of several of his colleagues. He was later persuaded to provide a personal account of his illness. This document, comprising his brave and harrowing diary entries, and the two Lancet articles are subjected to comparative literary analysis which clearly exemplifies the distinctiveness of the narrative approach to qualitative research.

The editor of an online teenage magazine invited a psychologist to join as the ‘agony aunt’ on its website. About two thirds of letters received referred to self-injury. These raw and often semi-literate postings provided such revealing insights into the thoughts and behaviours of their authors that a detailed analysis of their content was undertaken. This concluded that self-injury, which is of extraordinarily high prevalence, is a language of distress, a coping strategy rather than a mental health problem, although those who self-harm are at higher risk. A philosopher, Peter Goldie, offers an illuminating commentary on narrative discourse and its concerns with human values and emotions. He avows that ‘such discourse should not aspire to be dispassionate like scientific discourse’ but the final contributor to this section, Yiannis Gabriel, reminds us that narratives require interrogation like other claims to truth; that subjectivity does not automatically confer authenticity.

The ‘Counter-narratives’ are those which offer an alternative voice to that of an accepted medical formulation. The theme is explored persuasively in relation to several topics including the ‘shaken baby syndrome’ and the unfortunately-named ‘Munchausen syndrome by proxy’. Less dispassionate than these contributions is a chapter relating to the vexed question of organ retention. Representation of the imperatives of pathological enquiry is contrasted with the perspectives of parents of children whose organs were removed. It is written in language which clearly identifies the author with such perspectives.

The ‘Meta-narratives’ section tackles issues of wider dimension. It comprehends problems of mental health legislation, disability, risk analysis, priorities and inequalities in health care, all within the framework of the narrative paradigm.

At the end of their introductory chapter, the editors express the hope that in the variety of interdisciplinary methods and conceptual frameworks which the volume encompasses, ‘it properly and comprehensively displays the state of narrative studies in health at the start of the twenty-first century’. It undoubtedly succeeds in doing so and even the most sceptical reader will find both interest and enlightenment in its pages. One of the editors and chapter contributors, Trisha Greenhalgh, described in a column in the BMJ a visit to Tokyo where she received a welcome of celebrity style and proportion, but ‘it turned out I wasn’t famous at all, except amongst a small group of off-beat academics who identify with my fringe ideas and irreverent style. Just like in Britain, then.’ This book might change things. It is not one for the bedside table; it is a sit-up-straight-and-pay-attention sort of book. Obedience to such instruction should be amply rewarding.

References

DAVID SHAW
Emeritus Professor of Clinical Neurology,
University of Newcastle upon Tyne