Book reviews

DEMOCRATIZING HEALTH. CONSUMER GROUPS IN THE POLICY PROCESS
Edited by Hans Löfgren, Evelyne de Leeuw and Michael Leahy
2011 Edward Elgar. ISBN 978 1 84844 784 4
10.1071/AHv36n3_BR1

One of the greatest strengths of this book is the quite remarkable spread of contributors from across the globe. The three editors – all from our own Deakin University – are to be congratulated for managing to get such a broad international array of authors and country experiences. And these matter for such a book. They matter first because the issue of democratising health is a genuinely international one; second in any country’s agenda for pursuing such democratisation there are lessons to be learned from other countries; and third, as it turns out, experiences across countries vary quite a bit.

I enjoyed the book and found it a most useful addition to the literature in this field. In reviewing it, however, I need to declare a particular bias with respect to democratising health. I see citizens as being those who would be involved in such a process and I prefer to draw a clear distinction between citizens and consumers. (I will return to that issue shortly.)

The book, for an edited volume with 16 chapters, is very readable. That is quite something when it covers such a range of very different countries from the USA to Malaysia, from Austria to Australia.

The book opens with the following statement from the editors:

‘This book examines the extent to which consumer groups engage in the development of policy affecting their members’ health and health care. Such engagement may be referred to as the “democratisation of health” but, as the contributions to this book show, there are considerable differences between national contexts as to what this means, both in theory and in practice.’

(p. 1)

The editors suggest that there are two streams to democracy ‘the liberal or the social stream’ but that, whichever is adopted, democracy ‘is perceived rightly or wrongly as the only form of government capable of giving due recognition to human dignity’.

(p. 2)

Beyond the introductory chapter, Milewa discusses health activism in the age of governance and interestingly concludes that ‘health activist groups exist only because their aims have not been met in the context of the political, bureaucratic and medical status quo.’ (p. 27)

The majority of the other chapters have a specific country focus. For Malaysia, Barracough and Kai Lit show how, in the wake of the adoption of neo-liberal ideology and policies, including privatisation, the role of consumer groups changed. ‘Their role in monitoring “value for money” and quality of care was intensified by the rapid growth of private hospitals and the more intensive use of medical technology’ (p. 164). It was then perhaps inevitable that they became embroiled in ‘an ideological challenge to the government’s stated goals of reducing the public financing of health care and privatising the public agencies responsible for its delivery’ (p. 164).

Church and Armstrong worry about the role of citizens in Canada generally, but also specifically with respect to healthcare where they claim that consumer groups have increasingly been driven into ‘an unholy alliance with private corporate concerns’ (p. 205) and they call for ‘a greater sense of organic citizenship’ (p. 205) in Canada.

There are two chapters on the USA, one by Fox and Lambertson is quite despairing of the role of health consumers to date – but they take heart from the Obama reforms that their voice can make a difference; they end on a positive note, ‘If a strong consumer voice continues to develop … this nascent voice [can] gradually weave its way into the fabric of American political dialogue’ (p. 219). The chapter by Daw, Truong and Roseau presents a more positive face of the consumers’ role in the USA, but not one that suggests they have much impact on health policy.

Reading through the various contributions in the book I gained an increasing sense of unease on one particular front. I simply had not realised the extent to which various industry vested interests have infiltrated consumer groups. In retrospect I concede that not to have thought this through shows a degree of naivety on my part, especially as I am often ready to see such infiltration in healthcare policy-making more generally.

Having been alerted in this way to the potential problems of industry sponsorship of consumer groups, I was particularly fascinated by the concluding chapter from Vitry and Löfgren on the pharmaceutical industry and health consumer groups.

I am sure it was not appropriate for me to chuckle when I read early in the chapter that it is ‘increasingly acknowledged by both corporations and consumer groups that their interactions must be consistent with ethical standards’ (p. 239). The consumer groups certainly; but the corporations? Corporations by law must seek to serve their shareholders. How they can ethically do that and foster the objectives of healthcare systems seems to me, at best, questionable.

Frighteningly the extent of involvement of corporations in sponsoring consumer groups is quite extraordinary. Vitry and Löfgren report that ‘between a third and two thirds of health consumer groups in developed countries receive corporate support in some form’ (p. 240). They conclude, ‘the drawbacks of industry partnerships require new initiatives for independent funding of consumer organisations and clear rules for managing conflicts of interest in governmental, research and health services institutions’ (p. 251).

‘Clear rules’? I think only one is needed. There should be no industry sponsorship of consumer groups!

And again, reading about this industry sponsorship of consumer groups serves to strengthen my preference for citizens rather than consumers in democratising health.
The worry about all of this is that consumers are simply that. When I, as a consumer, think about healthcare, then I want the best for myself and my family. Information from consumers has its uses, but for me, what this book does not do adequately is to distinguish between citizens and consumers. And that matters. In the role of citizens people think more broadly and about others’ health and others’ access to healthcare (as I have seen in working with citizens’ juries). They can get into considerations of, for example, equity which is not an issue for a consumer.

The editors write in the first chapter, ‘In capitalist economies the term ‘consumer’ has for many come to mean a purchaser of goods and services in markets, and thus to connote the rights attendant upon that role. But this term had an ordinary language meaning before this market sense became so dominant, and it retains sufficient currency to permit its use today in a volume like this one’ (p. 2). I disagree – I fundamentally disagree! But let the reader be the judge of the editors’ stance on this question.

The book is good and I recommend it strongly. What it does for me – even if not the editors’ intention – is to reinforce my view that there is a need to distinguish very clearly between consumers and citizens and that the issue of democratising health should lie in the hands of citizens and not consumers.

Professor Gavin Mooney

This book is not be taken on lightly. It is scholarly in terms of its approach and content but covers a wide variety of contexts and situations. It is essential reading for all those that work in healthcare or violent settings and mandatory for those researching violence. It is multidisciplinary and interdisciplinary in the true sense, it borrows and critiques theories and methodologies across and between disciplines.

As we are told from the beginning, violence is addressed throughout the book. It is overt and covert, public and private and perpetuated professionally across a range of settings. For someone who has worked in healthcare for so many years and who assumed that the overt violence that I experienced in the past has decreased over time, it was confronting to find that while this might be so on the surface, covert violence is still alive and thriving, although perhaps we are just beginning to name violence in some of its forms.

Modern forms of violence arise out of modern situations. A rapidly changing society in terms of cultures, ethnicity, skin colour, faiths, rituals, beliefs and commentary, poses its own challenges and threats. Fear is the underlying emotion. Fear about difference and diversity. Healthcare professionals in Australia are no longer white, middle class men and women, but come in all different guises. As Rudge et al. highlight, in their chapter ‘The violence of tolerance in a multicultural workplace’ (pp. 31–46), “the very act of tolerance is experienced by racialised groups as an act of violence.”

The well-documented areas of violence, such as forensic and mental health settings, are analysed along with the use of therapeutic interventions and their outcomes. The contemporary discourse concerning bullying is continued in this text with an emphasis on bullying of nurses in the workplace and on telephones while elder abuse, not openly spoken about, is opened up to scrutiny and critique. The importance of elder abuse has been identified by a World Health Organisation report, where it was labelled “one of the leading global public health issues and societal problems of our time” (p. 107).

I highly recommend this text for graduate students in a range of studies, not only health care. It is a very important book in terms of the empirical work included in its pages and the critical perspective taken by the writers. Those working in and researching any area of violence will find the text a worthy addition to their library.

Professor Judy Lumby AM

Director Joanna Briggs Foundation, Emeritus Professor and Honorary Professor The University of Sydney, Sydney, NSW, Australia.
EVIDENCE-BASED HEALTHCARE IN CONTEXT: CRITICAL SOCIAL SCIENCE PERSPECTIVES

Edited by Alex Broom and Jon Adams
2012, Ashgate ISBN: 9780754679813
10.1071/AHv36n3_BR3

The notion of evidence-based healthcare is now so ubiquitous as to be largely unquestioned as a desirable part of the health landscape. After all, who would not want to have evidence-based care? As Broom and Adams state, evidence-based medicine is a ‘seemingly benign concept’, the complexity of which only emerges when consideration is given to what constitutes evidence, and what is included in, or excluded from, evidence-based frameworks. Broom and Adams have brought together a range of authors to present critical social science perspectives, thus providing a timely reminder that what may be viewed as scientific and objective is, in fact, part of health and care systems that are integrally embedded in social systems.

Broom and Adams set the scene in their introduction in which they state that, ‘Evidence-based paradigms now fundamentally shape the way health service providers, health funding bodies, governments and policy makers view ‘effectiveness’, and their willingness to fund and support interventions, practices, models of care and practitioners’ (p. 3). The purpose of a critical social science perspective is to ‘…examine how the principles, technologies and practices of ‘evidence based approaches’ may allow certain things and promote certain understandings of health and illness while silencing others’ (p. 3). There is a diverse array of fields in which notions of evidence-based have become integral to policy and funding decisions, all of which can highlight different aspects of the key debates. Following an introduction which provides an excellent overview of the key debates about evidence, the text is divided into three parts.

Part one, ‘Evidence in cultural and theoretical context’, contains two chapters. The capacity for clinicians to understand, interpret and use evidence is at the heart of the chapter by Timmermans and Angell. In the context of uncertainty, what does evidence offer to new practitioners and how do they weigh it up against other sources of knowledge? Much research has been undertaken on how knowledge is learnt and exchanged in the clinical setting and this study points to different ways in which new practitioners use evidence. The second chapter in this section by Holmes and O’Byrne problematises the notion of evidence by drawing on theories that can help unpack ideologies about knowledge, power and stratification. Evidence-based medicine is critiqued for its dominance in knowledge construction. This chapter sits well within part one, providing a theoretical examination of evidence, but knowledge of social theory is needed to really grasp the arguments that are being made, and there needed to be a clearer fit with all other chapters (which are largely empirically-based).

In part two ‘Evidence in the clinic’, three chapters highlighting different clinical settings are presented. Brattheim, Faxvaag and Tjora explore the nature of ‘situational knowledge’ using the example of aorta implant surgery to argue that attention to context and communal bases of expertise must be acknowledged to understand knowledge (and evidence) transfer. Similarly, the use of tacit knowledge drawing on the example of neurorehabilitation (Flynn et al.) demonstrates how evidence put into practice is interpretively experienced and acted on. The differential use of evidence between two medical specialties (oncology and haematology) and by nursing (Broom and Adams) demonstrates how the disciplinary context made up of a complex mix that includes professional identity, organisational culture and individual judgment all shape views about evidence.

Part three, ‘Evidence on the margins’ is the strength of the text. It is here that understandings of evidence are problematised from a range of perspectives. Dew provides an excellent overview of contemporary debates about legitimacy and standardisation and demonstrates how some practitioners respond to the ‘crisis of evidence’ drawing on interviews with general practitioners who incorporate a range of complementary and alternative therapies into their medical practice. In an era where patient-centred care is deemed an important approach, Broom and Tovey discuss the non-linear way that cancer patients approach ideas about evidence. The final chapter in this section focuses on midwifery practice. Homer and Broom situate the evidence-based movement within its political context and provide a compelling discussion of how evidence is shaped in an environment that is contested in terms of who should provide health care and how should it be carried out.

This text will be of interest to all of those interested in understanding how the notion of evidence plays out in practice. I see it as being particularly useful as a text for advanced students of health sciences, who must learn how to read and critique health research. I think that it suffers a little from the problems of many edited texts. There needs to be some continuity between arguments in different chapters and the quality of chapters, while generally high, is uneven. There is also a need to move beyond how healthcare providers resist or reinterprets evidence-based health care (and some of the small qualitative studies used to highlight these important issues did not appear able to move beyond initial exploration of the issues) to examine in detail how we can think about implications for healthcare practice of such resistance/reinterpretation. I would have liked more about how critical social science perspectives can be used to shape the debate and to that end the concluding chapter by Anne-Grete Sandaunet and Evan Willis was particularly interesting. However, reading the book as a whole, one does get an overview of the key issues across a range of healthcare settings and issue and to that end, it provides a valuable contribution to the field.

Karen Willis
Faculty of Health Sciences, University of Sydney, Sydney, NSW, Australia.

www.publish.csiro.au/journals/ahr