

# Introduction to the Special Issue

## Negotiating Care in Uncertain Settings and Looking Beneath the Surface of Health Governance Projects

*Roberta Raffaetà and Mark Nichter*

Two intersecting trends in healthcare related to the biopolitics of responsibility have been noted by medical anthropologists: increasing health governance enabled by audit culture, and the holding of individuals more accountable for their health in concert with the principles of neoliberalism and ready access to a proliferation of information sources. On the one hand, governments have continued to exercise governance in areas of health that fit political and economic agenda. Two good examples of the latter trend are bio-nationalism projects such as Japan's insistence that Japanese bodies are unique and that clinical trials be conducted on commensurate bodies in order for drugs to be approved for use by the Japanese population (Kelly and Nichter 2012) and Erten's article in this volume on the biopolitics of Caesarean-section deliveries in Turkey. In Turkey, recent limitations placed on high rates of Caesarean sections, and state monitoring of child birth, have less to do with the risks of the procedure and the best interests of women, and more to do with the State's pronatalist agenda and desire for each woman to have four children, more children than Caesareans safely allow. The other trend is characterised by health citizenship where the public is asked to be more proactive in promoting health and preventing disease, and patients are increasingly being asked to take on more responsibility and participate more actively in healthcare decision-making. This is occurring at a time when regulation of the healthcare market is being debated as well as manipulated such that health 'goods', 'bads' and 'fads' abound. In today's 'risk society' marked by crises of trust and reflexive modernisation (Beck 1992) as well as a lucrative harm-reduction industry that thrives on chronic doubt, 'buyer beware' is replacing 'blind trust' in healthcare providers, hos-

pitals, insurance companies and agencies responsible for protecting the health of the public. Citizens are increasingly expected to become informed agents exercising reasonable judgement and freedom of choice (Briggs and Hallin 2007; Lindsay and Vrijhoef 2009; Rogers 2009). Needless to say, this is a Herculean task given the rapid rate of scientific advances, highly publicised promises of medical breakthroughs that often do not materialise, rampant disinformation and conflicts of expert opinion. This has led members of the public to search for information filters which they can trust, be these personal networks, expert bodies or favourite news outlets.

Once thought of as powerless and subject to paternalistic medicine, patients are being reconfigured as both partners in healthcare decision-making and as possessors of biovalue in the form of genetic material, body parts and disease experience in local and global medical marketplaces. Okamoto's article in this issue reviews stages through which a shared decision-making model of doctor-patient has emerged and an emphasis on patient compliance has shifted to adherence and concordance with negotiated care plans. Abdalla's article draws our attention to yet another outcome of patient participation in the healthcare market of Egypt. He expands the scope of biovalue to include patients' sale of patient disease experience to medical students who have limited opportunity to gain this knowledge in Egyptian medical colleges. During medical school, real-world patient exposure is limited, and students are left to fend for themselves in terms of gaining practical experience. Impoverished patients generate income for their daily survival by trading in the biovalue of embodied knowledge of their health conditions for sale to medical students at a cost. On the one hand this seems like a mutually ad-



vantageous arrangement, but on the other hand it undermines doctor–patient relations based on trust, and does not give medical students the opportunity to learn the communication skills needed to accomplish this in practice.

At first glance, the two broad trends noted above appear to be divergent: one imposing state power and the other promoting individual responsibility and informed healthcare choices. Researchers contributing to this volume argue, instead, that these trends often reinforce one another and preserve long-standing asymmetries of power. In today's shifting healthcare landscape, practitioners are increasingly being encouraged to practice both evidence-based medicine and patient-centred care as a means of achieving high marks for quality of care, promoting adherence and attracting patients in competitive healthcare markets. Indeed, in a recent special issue of the journal *Anthropologie & Santé* on the new role of patients in neoliberal states, Bureau and Hermann-Mesfen (2014) have argued that patient-centred medicine has become just another repackaged way medical dominance reproduces itself. As noted by these and other researchers (Fox et al. 2005; Wilson et al. 2007), patient experience is most commonly paid credence by biomedical professionals when patient experience maps well onto existing logics of biomedical practice. By and large, they argue, it is still members of the medical establishment who determine what constitutes evidence, what outcomes are desired, what options are deemed viable to consider, and what constitutes best practice despite rising interest in 'patient-reported outcomes' (PROMS). Articles by Okamoto and Salhi in this special issue support this view. They describe clinician definitions of 'good patients' as patients who are docile, non-demanding and for whom care management requires little if any negotiation – the hallmark of treatment adherence. Agency is delimited to a circumscribed set of choices concordant with the dictates of evidence-based medicine while other options not legitimated by standardised tests of efficacy (such as randomised controlled trials, meta-analysis and so on) are dismissed. As Greco (2004: 16) noted, 'a right to health ... must envisage, as part of its remit, governmental provisions for a different way of interacting with scientists as well as other practitioners, aimed at eschewing any automatic privilege or monopoly over the claim of rationality'.

A third rising trend in healthcare is also noted by articles in this volume: the impact of healthcare austerity. Austerity measures make it difficult if not impossible for the afflicted to follow through on recommended or desired courses of action that transfer greater respon-

sibility to the afflicted and their families. Families of those afflicted with chronic conditions requiring home care and/or rehabilitation are often placed in structurally vulnerable and precarious positions (Quesada et al. 2011). Sakellariou's article addresses this phenomenon by documenting how people in the U.K. living with motor neurone disease, a chronic and incurable condition, have to bear many of the costs for the self-management of this condition. This points to the difference between the provision of universal healthcare and social care and support services in the U.K. Lack of social support for the afflicted and their families is a far-reaching problem related to vital politics and bioeconomy (Lemke et al. 2011) and in this case decisions about what kinds of people warrant an investment of significant resources at times of austerity. Being asked to take on responsibility for the care of those deemed unworthy of state investment places family caretakers at significant risk of psychosocial distress.

Reduced funding for primary care and for the structurally vulnerable undermines the ability of citizens to take care of themselves leading to higher levels of morbidity and greater personal and national healthcare costs over time. This takes a toll on healthcare providers working on the front lines as well as the patients they see during acute episodes of illness. This is brought home by Salhi's article on emergency rooms in the United States. Many U.S. citizens and undocumented workers turn to emergency rooms for primary healthcare needs either because they lack insurance in a system without universal access to healthcare or are unable to get an appointment with over-scheduled and overworked clinicians. Emergency rooms are not designed to meet the primary care needs of patients as the doctors staffing them are tasked with identifying, managing and triaging health crises, yet healthcare structures effectively require them to respond to those needing primary care. They follow procedures typically driven by treatment algorithms designed to rule out life-threatening diseases and injuries. Emergency-room doctors focus on medical risk, and demonstrate their competence by efficiently and effectively constructing cases based on verifiable facts. ERs are safety nets for healthcare systems. They are not an appropriate place for patient-centred care tailored to the needs of local populations, nor for dealing with conditions that lead to chronic ill health. The quality of care offered by emergency-room doctors is often questioned by patients, who have different perceptions of their role and expectations of services provided.

Articles in this volume further draw attention to the awkwardness of distributing responsibility when

medical information is uncertain. In this era of rapid scientific discovery and information circulation, science increasingly appears to be unfinished (Hess 2004) and differences of opinion about appropriate courses of action abound (Latour 2013), leading to tensions captured by studies of bio-communicability (Briggs and Hallin 2007) that draw attention to the production, circulation and reception of alternative sources of health-related knowledge. In an era of biotech advances, nature and culture are densely interpolated and biological ‘facts’ often become a matter of social and moral judgement about which kind of lives are worth living (Rabinow 1992; Rose 2001). Informed choice becomes problematic. Doctors are expected to inform patients about objective facts, but the facts they access are often based on aggregate populations, which serve the ends of population-based medicine. These studies are not designed to predict individual outcomes. And as many medical anthropologists studying in clinical settings have noted, doctors’ advice is often tempered by their own social and cultural assumptions, as well as by their perceptions of who their patients are, the kinds of lives they lead, what they are capable of understanding and so on (Carpenter-Song et al. 2007; Gregg and Saha 2006; Kleinman and Benson 2006; Taylor 2003). In ‘cases’ where the cause and treatment of a medical problem appear clear doctors tend to offer strong advice and disregard the social and cultural dimensions of illness experience as superfluous and the objectification of patients as necessary (Good and Good 1989). In other cases when a problem is indeterminate or a treatment less certain, doctors appear far more willing to negotiate with patients or let them experiment. This latter case is apparent in Okamoto’s article, which illustrates what happens in the field of renal medicine since the option of conservative care was added to traditional renal replacement therapy options (haemodialysis being the most practiced). Conservative care provides control of symptoms, management of anaemia and end-of-life/palliative care. Both interventions have advantages and disadvantages, but since conservative care has been introduced only recently it is difficult for medical professionals clearly to assess its impact and consequences on people’s health and life expectancy. Okamoto points out that even when choice over a treatment is characterised as shared and negotiated between medical professionals and the patient, in practice the burden of choice often falls to patients when there is no definitive best course of action.

The importance and ramifications of patient categorisation resurfaces several times in the ethnographies comprising this special issue: ‘easy’ versus

‘difficult’ patients (Okamoto), high- versus low-risk patients (Salhi), patients entitled to have care versus those who are not included (Sakellariou), patients as bearers of disease knowledge (Abdalla) and patients seen through the lenses of ethnic categorisation (Erten). Medical professionals and the institutions in which they work slip between treating patients as individuals and as cases bearing disease labels that influence care provision. Once labels are consciously, unconsciously or administratively adopted as a matter of audit, the complexity of the individual patient begins to be lost. Treating all bodies as universal and alike erases the importance of local biology even when the importance of epigenetics and pharmacogenetics is acknowledged (Lock 2013; Marks 2012). And, as noted by Mol (2008), to care for the afflicted is a difficult task given that bodies are unpredictable and complex assemblages. Treating the ‘disease’ as a bounded entity is, however, easier to manage and allows practitioners to maintain personal boundaries and emotional detachment, aspects of care provision that may well be important for the wellbeing of practitioners (Good and Good 1989).

Given health transition, and the spectre of rising numbers of people afflicted with chronic and indeterminate illness as well as states of comorbidity, the medical professional’s role is shifting in response to new challenges that lie outside the preview of specificity-oriented medicine. In many cases, information about risk, a disease or a medical intervention appears abstract to the individuals trying to understand how information being conveyed relates to their particular situation. Indeed, presented with population-based information, patients often ask doctors for their experience with patients they have treated more like them, not a population they cannot imagine. And in some cases, patients or their families feel being given more information may actually place them at greater risk if it demoralises them and leads to their losing hope. As is made clear by articles in this special issue, providers and patients often have different matters of concern: providers with treating and identifying life-threatening diseases, adhering to best practices and presenting the objective facts as a matter of ethics; and sick people trying to personalise information, and better cope with their illness experience as it impacts on their lives and those of their caregivers.

Okamoto’s article on shared decision-making among elderly patients with end-stage renal failure in the U.K. speaks to this point. In principle, a shared decision-making model has been adopted and a choice has to be made between conservative care or renal replacement therapy. However, most of the time, med-

ical professionals limit themselves to informing patients about risks and advantages not firmly established by clinical evidence. Patients are left with the 'burden of choice' and practitioners, despite the release of responsibility, feel unease because they are aware of the partiality of their contribution and the ambiguity of the medical information they can deliver. The article also documents the complexity of such choices. Sometimes patients change their mind over the course of the therapy, complicating a care management system designed to work best when definitive choices over treatment are made and adhered to over time.

Sakellariou's article documents rigidity on the part of medical institutions in the U.K. to implement patient-centred care in practice. Medical institutions organised to manage categories of patients often fail to meet the individual needs of patients looking to live their lives on their own terms, as best they can. Drawing from a narrative study of a woman suffering from motor neurone disease (MND), Sakellariou presents us with the story of Arleen as she struggles to 'to be me first and my illness second'. Her case exemplifies an individual who refuses to be reduced to and managed as a disease category. She must fight to have her voice heard, often without success, as medical and legal institutions reject her requests for the types of assistance she feels will serve her best. Arleen feels her requests are discounted because the nature of her disease is not deemed worthy of additional public expenditures. The crucial issue in Arleen's case is not just 'who decides' but who (not just what) is considered worthy. Sakellariou leads us to think about how Arleen's last days matter, and what it says about society when decisions about quality of life (and death) are determined by patient-far rather than patient-near considerations and compassionate care.

The two ethnographies included in this volume that take place outside of Western Europe and North America lead us to think about the politics of responsibility for healthcare in two different but important ways. In the case of medical students' experiences in Egypt described by Abdalla, professional patients' sale of embodied disease-related knowledge to students is needed given the poor resources allocated by the state for appropriate medical training and for the opportunity of hands-on experience with sick people. Universities tolerate, if not condone, these kinds of exchanges. Abdalla shows how these encounters create both dependency and agency on the side of the students as well as on side of the patients. This case study sheds light on emerging forms of biological exploitation and commodification of the body in contexts of

health disparity and the various forms through which both biological exploitation and biological agency are co-productive processes.

The case is also a testimony about the dire need for health-system strengthening beginning with the training of young doctors. It speaks to the wisdom of the Indian proverb 'better to consult an experienced patient than a young doctor' when thinking about how primary healthcare can be provided to the poor in low- and middle-income countries. In such countries, it is often argued that an important part of providing 'primary healthcare to all' is compulsory service by young doctors when they graduate from medical school. Many young doctors, however, resist such service not simply because it is arduous or because the places they are asked to work lack basic amenities, but out of fear, a subject little acknowledged in the literature. In Egypt, as well as in countries like India (Nichter's long-term field site), young doctors are not trusted by the public for apparently good reasons, given their lack of practical knowledge. Even when posted to government clinics, many patients chose to forego their services and consult private practitioners, be they institutionally trained or – in the case of India – members of a large population of self-trained medical practitioners. Young doctors fear both making errors and the reprisal of family members of the afflicted if cases go from bad to worse. This fear leads them to refer patients whenever a case seems serious, supporting the image that they know little. Medical students able to get coveted postgraduate training gain plenty of experience, but young medical students feel insecure in their knowledge and are not well respected by the public.

The second such ethnography, provided by Erten, focuses attention on attempts being made by the political party currently in power in Turkey to regulate Caesarean-section deliveries. Since 2012 the Turkish State began strongly advocating for a substantial reduction of the country's high rate (one of the world's highest) of Caesarean sections, which culminated in an attempted ban on elective Caesarean sections. On the surface this effort is in line with WHO reproductive health recommendations and would constitute a significant cost- as well as life-saving measure as Caesareans above the WHO recommended level increase serious risks to mothers and subsequent infants, as well as increasing healthcare costs. It also appeared to be part of a larger state agenda supporting: (1) an expanded sense of health citizenship through the regulation of tobacco and alcohol consumption, forms of health promotion that would lead to health-cost reduction; and (2) ideas about women's role in domestic

healthcare as the moral centre of the family and of the nation. Erten's interviews with medical professionals point to an entirely different motivation for the policy tied to the pronatalist discourse promoted by the AKP (Justice and Development Party) led by Prime Minister Recep Tayyip Erdogan. Erten's ethnography draws our attention to the selective nature of reproductive health discourse in Turkey. This discourse at once stigmatises the 'uncontrolled' fertility of Kurdish women for not being responsible enough to choose how many children to birth, and encourages ethnically Turkish women to bear more children as their duty to the state. Reproductive health policy serves a nationalist agenda aimed at producing more of the right kind of citizens. This is a powerful illustration of biopolitics that demonstrates the necessity of investigating 'how and why' policy is being implemented in context.

To conclude, the articles included in this special issue encourage us to look at the social relations and biopolitics of encounters between patients, medical professionals, medical institutions and the state and to carefully interrogate shifts in the distribution of responsibility for healthcare and all it entails. We must look beneath the surface and at the intersection between seemingly top-down and citizen-proactive governance policies.

*Roberta Raffaetà is lecturer in medical anthropology at University of Milan-Bicocca and in cultural anthropology at Verona University, Italy. In her doctoral work (University of Lausanne, 2008) she explored how different actors in Italy make sense of allergy, dealing with issues of medical pluralism, health governance, embodiment and identity. Since 2009 she has conducted research on migration, working for Monash University (Australia) on Chinese settlement in the city of Prato (Italy) and, thanks to a Marie Curie Fellowship, on Moroccan and Ecuadorian families in northeast Italy. She pursues an ecological understanding of the migratory experience, exploring how the body, the senses/affect and place/space matter in issues of identity, citizenship and participation. She is now developing a new project on gluten-related sensitivities. E-mail: Roberta.Raffaeta@unitn.it*

*Mark Nichter is Regent's Professor and coordinator of the Graduate Medical Anthropology Training Program at the University of Arizona. He received a BA in philosophy and psychology at the George Washington University (1971), a PhD in social anthropology (University of Edinburgh, 1977), an MPH in International Health (Johns Hopkins School of Public Health, 1978), and postdoctoral training in clinically applied anthropology (University of Hawaii, 1980–1983). He holds joint appointments in the Depart-*

*ments of Family and Community Medicine and the College of Public Health at the University of Arizona. Dr Nichter has been the recipient of several prestigious awards in the field of anthropology including the American Anthropology Association's Margaret Mead Award, the Society for Medical Anthropology's Career Achievement Award, and the Wellcome Institute Medal for Applied Medical Anthropology. E-mail: Nichtermark@gmail.com*

## Acknowledgments

The first joint conference between the EASA Medical Anthropology Network and the AAA Society for Medical Anthropology, titled 'Encounters and Engagements: Creating New Agendas for Medical Anthropology' took place on 12–14 June 2013 at the Universitat Rovira i Virgili of Tarragona, Spain. Inspiration for this special issue came from Stream 4 'Uncertainty, Intuition and Trust', which saw the participation of more than fifty scholars from all over the world who contributed to a lively and stimulating discussion; we would like to thank all of them.

The present introduction is the outcome of joint and indivisible work by the authors; however, if for academic reasons individual authorship is to be assigned, Roberta Raffaetà wrote the first half and Mark Nichter the second half.

## References

- Beck, U. (1992), *Risk Society: Towards a New Modernity* (London: Sage).
- Briggs, C. L. and D. C. Hallin (2007), 'The Neoliberal Subject and Its Contradictions in News Coverage of Health Issues', *Social Text* 93, no. 25: 43–65.
- Bureau, E. and J. Hermann-Mesfen (2014), 'Patients contemporains face à la démocratie sanitaire', *Anthropologie & Santé* 8 [Online] URL: <http://anthropologiesante.revues.org/1342>
- Carpenter-Song, E., M. Schwallie and J. Longhofer (2007), 'Cultural Competence Reexamined: Critique and Directions for the Future', *Psychiatric Services* 58, no.10: 1362–5.
- Fox, N. J., K. J. Ward and A. J. O'Rourke (2005), 'The "Expert Patient": Empowerment or Medical Dominance? The Case of Weight Loss, Pharmaceutical Drugs and the Internet', *Social Science and Medicine* 60, no. 6: 1299–1309.
- Good, M.-J. DelVecchio and B. J. Good (1989), 'Disabling Practitioners: Hazards of Learning to Be a Doctor in American Medical Education', *American Journal of Pathopsychiatry* 59, no. 2: 303–9.

- Greco, Monica (2004), 'The Politics of Indeterminacy and the Right to Health', *Theory, Culture & Society*, 21, no. 6: 1-22.
- Gregg, J. and S. Saha (2006), 'Losing Culture on the Way to Competence: The Use and Misuse of Culture in Medical Education', *Academic Medicine* 81, no. 6: 542-7.
- Hess, D. J. (2004), 'Medical Modernisation, Scientific Research Fields and the Epistemic Politics of Health Social Movements', *Sociology of Health and Illness* 26, no. 6: 695-709.
- Kelly, K. and M. Nichter (2012), 'The Politics of Local Biology in Transnational Drug Testing: Creating (Bio) Identities and Reproducing (Bio) Nationalism through Japanese "Ethnobridging" Studies', *East Asian Science, Technology and Society* 6, no. 3: 379-99.
- Kleinman, A. and P. Benson (2006), 'Anthropology in the Clinic: The Problem of Cultural Competency and How to Fix It', *PLoS Medicine* 3, no. 10: 294.
- Latour, B. (2013), *Cogitamus. Sei lettere sull'umanesimo scientifico* (Bologna: Il Mulino).
- Lemke, T., M. J. Casper and L. J. Moore (2011), *Biopolitics: An Advanced Introduction* (New York and London: NYU Press).
- Lindsay, S. and H. J. M. Vrijhoef (2009), 'A Sociological Focus on "Expert Patients"', *Health Sociology Review* 18: 139-44.
- Lock, M. (2013), 'The Epigenome and Nature/Nurture Reunification: A Challenge for Anthropology', *Medical Anthropology: Cross-cultural Studies in Health and Illness* 32, no. 4: 291-308.
- Marks, J. (2012), 'The Biological Myth of Human Evolution', *Contemporary Social Science: Journal of the Academy of Social Sciences* 7, no. 2: 139-57.
- Mol, A. (2008), *The Logic of Care: Health and the Problem of Patient Choice* (London: Routledge).
- Quesada, J., L. Kain Hart and P. Burgois (2011), 'Structural Vulnerability and Health: Latino Migrant Laborers in the United States', *Medical Anthropology: Cross-cultural Studies in Health and Illness* 30, no. 4: 339-62.
- Rabinow, P. (1992), 'Artificiality and Enlightenment: From Sociobiology to Biosociality', in *Incorporations*, (ed.) J. Crary and S. Kwinter (New York: Urzone), 234-252.
- Rogers, A. (2009), 'Advancing the Expert Patient?', *Primary Health Care Research and Development* 10, no. 3: 167-76.
- Rose, N. (2001), 'The Politics of Life Itself', *Theory, Culture and Society* 18: 1-30.
- Taylor, J. S. (2003), 'Confronting "Culture" in Medicine's "Culture of No Culture"', *Academic Medicine* 78, no. 6: 555-9.
- Wilson, P. M., S. Kendall and F. Brooks (2007), 'The Expert Patients Programme: A Paradox of Patient Empowerment and Medical Dominance', *Health and Social Care in the Community* 15, no. 5: 426-38.