

A Miles Little Reader

# RESTORING HUMAN VALUES TO MEDICINE

Editors

Ian Kerridge

Christopher Jordens

Emma-Jane Sayers

DESERT PEA PRESS

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Assignments of meaning  
in Epidemiology

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## Foreword

*The Hon Justice Michael Kirby AC CMG was appointed to the High Court in 1996. At the time of his appointment he was President of the New South Wales Court of Appeal. He also served as the first Chairperson of the Australian Law Reform Commission from 1975 to 1984. He has held numerous national and international positions including the UN Special Representative in Cambodia and as President of the International Commission of Jurists. One of the worlds top legal minds, he is well known for his compassion and commitment to social justice.*

### *Miles Little: thinking globally, acting personally*

The retirement of Emeritus Professor Miles Little as Inaugural Director of the Centre for Values, Ethics and Law in Medicine is a watershed in Australia's attention to bioethics. I am proud to be associated with the collection of works that will reflect his luminous contributions to thought and action concerning medicine and ethics.

An examination of Miles Little's articles on the topics of bioethics indicates his abiding concern with the universal questions that confront those working in the field. He addresses the issues of honour and personal dignity;<sup>1</sup> the triage problem and the making of medical decisions by reference to economic considerations;<sup>2,3</sup> the centrality of informed consent to medical treatment;<sup>4</sup> the meaning of life and, where there is unbearable suffering, the legitimacy of assisted suicide;<sup>5</sup> the inter-action of ethical values in the performance of medical practice within the law;<sup>6</sup> and the particularity of bioethics in various contexts, including that of the treatment of indigenous peoples, especially of the Aboriginal people in Australia.<sup>7</sup>

All of these are crucial questions and all demand attention at a time when questions of bioethics have become even more complex and more urgent.

Every lawyer who has ever been engaged in a case involving treatment and medical practice soon realises the interaction of law with ethics in framing the appropriate, permissible or even legal responses to a medical crisis. My appreciation of the issues of medical ethics became more acute when I was appointed Inaugural Chairman of the Australian Law Reform Commission. Many of the tasks of that Commission engaged us in examination of bioethical concerns. The seventh report of the Commission in 1977 concerned *Human Tissue Transplants*.<sup>8</sup> In it, we examined the bioethics of transplant technology. This took us directly to the meaning of life, to end of life decisions and the appreciation of death as a process rather than an event. The Commission's report was highly successful,

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becoming the foundation for law reform statutes in all parts of Australia and also being copied overseas. The enterprise taught me that, whereas in most areas of the law national or regional peculiarities were to be expected and applied, in issues of bioethics the lawyer and lawmaker had to face the universal concerns presented by a universal biology.

More recently I have had these lessons reinforced by service on the Ethics Committee of the Human Genome Organisation and the International Bioethics Committee of UNESCO. The rapid advance in the Human Genome Project and the developments of genomics as a science have presented many complex questions that open new vistas and present novel dilemmas for the bioethicist.

Amongst new dilemmas are those concerned with protecting the privacy of genetic data; its accessibility to insurers, employers and the state; the manipulation of embryos by pre-implant technology in order to remove unwanted features that cause premature death or unacceptable suffering or disadvantage; therapeutic and reproductive cloning in the human species; the extraction and manipulation of embryonic stem cells; and the highly controversial question involved in patent protections for the discovery, identification and utilisation of genomic sequences.

Miles Little has understood all these developments. In many of his contributions he has examined them in the context of global debates about bioethics. His successors will be increasingly engaged in the debates about these international dilemmas, armed with his insights.

But what has strengthened Miles Little's contribution has been his strong foundation in hands-on treatment of actual patients and a concern for their well-being as whole persons – not simply manifestations of a given pathology. In this respect, he has evidenced the love of fellow human beings which, I believe, lies at the heart of universal human rights and the protection of human dignity – indeed respect for all forms of life and their inter-relationship in our fragile planet.

The issues of global technology are very puzzling, extremely important and highly controversial. Bioethicists of the future must devote their time and energy to those problems and offer solutions that will gain universal or widespread acceptance. However, it is also important, especially in the training of young people to be healthcare workers in the future, never to get too far from the individual patient. Thus, I believe, is something that Miles Little instils in his approach to bioethics. It is why he emphasises the importance of listening to patients and their families in their narratives of cancer illness. It is why he sees illness as a journey in which the physician and surgeon accompany the patient and the patient's family.

I have reason to know that this is Miles Little's approach. Fifteen years ago, when my mother fell ill with a lymphoma, Miles Little became involved in her case. Typical of the man, he drove me to Westmead Hospital in Sydney where my mother was waiting to see him. I can still see her in the large public waiting room, the sun streaming in as she sat quietly and resignedly reading a book in that green room – full of confidence that her doctors, like Miles Little, would do their best for her. And a belief that, whatever happened, it would be proper, with no unseemly struggle against nature or her fate.

In the world wide struggle for human rights, for economic equity and for peace and security, one frequently hears the aphorism that we should "think globally but act locally". In the field of bioethics we must do the same. We must adapt our thinking to the universal problems and the application of universal norms. Yet we must not neglect the hands-on need to respect human rights and human dignity and promote equity, peace and justice at the level of the individuals with whom we deal.

This is the approach that Miles Little has taken to values, ethics and law in medicine. In my view, it is the right approach. Fortunate is the Centre established in the University of Sydney to have had him at the helm as inaugural Director. I hope that his successors will go and do likewise – thinking globally, and acting with loving kindness to individuals in our immediate concern.

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Lindy Gaze, the administrative assistant at the Centre for Values, Ethics and the Law in Medicine, has been an invaluable member of the project team. In preparing the papers and the commentaries for publication, she combined efficiency and technical skill with humour, balance and wisdom.

Miles Little's work is embedded in the stories of ill people, and in the stories of those who care for and about ill people. We would like to acknowledge here (as Miles has done elsewhere) their vital contribution. We would also like to pay tribute to Penny Little and the family that she shares with Miles for the support that they have offered both to Miles and to the Centre for Values, Ethics and the Law in Medicine.

Finally, we would like to acknowledge the impact that Emeritus Professor Miles Little has had on each of us as mentor, critic, collaborator and friend. This reader is a way of thanking him for his way of working and for his way of being.

Ian Kerridge  
Chris Jordens  
Emma-Jane Sayers  
*Sydney, August 2003*

## Table of Contents

|                                                                                                                                            |      |
|--------------------------------------------------------------------------------------------------------------------------------------------|------|
| <i>Foreword</i>                                                                                                                            | v    |
| The Hon Justice Michael Kirby AC CMG                                                                                                       |      |
| <i>Acknowledgements</i>                                                                                                                    | viii |
| <i>Introduction</i>                                                                                                                        | 1    |
| Ian Kerridge, Christopher Jordens and Emma-Jane Sayers                                                                                     |      |
| <i>Part 1: Ethics in Medicine</i>                                                                                                          |      |
| 1 Is there a distinctively surgical ethics?                                                                                                | 9    |
| Commentaries by Michael Fearnside and Bernadette Tobin                                                                                     |      |
| 2 The fivefold root of an ethics of surgery                                                                                                | 21   |
| Commentaries by Russell Gruen and Paul McNeill                                                                                             |      |
| 3 Does reading poetry make you a better clinician?                                                                                         | 45   |
| Commentaries by Murray Bail, Jill Gordon and Stan Goulston                                                                                 |      |
| 4 Euthanasia and the meaning of a life                                                                                                     | 58   |
| Commentary by Roger Magnusson                                                                                                              |      |
| <i>Part 2: Philosophy and Medicine</i>                                                                                                     |      |
| 5 Assignments of meaning in Epidemiology                                                                                                   | 77   |
| Commentary by Alison Moore and Jason Grossman                                                                                              |      |
| 6 "Better than numbers ..."                                                                                                                | 103  |
| a gentle critique of evidence-based medicine                                                                                               |      |
| Commentaries by Rachel Ankeny and Fiona Mackenzie,<br>Les Bokey, Robin Downie, Natalie Gray, Steve Leeder,<br>Rob Simons and Melissa Sweet |      |

|    |                                                                                        |     |
|----|----------------------------------------------------------------------------------------|-----|
| 7  | Research, ethics and conflicts of interest<br>Commentary by Nancy Dubler               | 135 |
| 8  | Logic, hermeneutics and informed consent<br>(See commentary by Michael Carey)          | 151 |
| 9  | On trust<br>Commentary by Michael Carey and Merrilyn Walton                            | 166 |
| 10 | Resource constraints and moral pressures<br>(See commentary by Paul Gatenby)           | 196 |
| 11 | Ethnomics<br>Commentaries by Paul Gatenby and Gavin Mooney                             | 203 |
| 12 | Discourse communities and the discourse of experience<br>Commentary by Paul Komisaroff | 220 |

### Part 3: *Illness Experience and Survivorship*

|    |                                                                                                                 |     |
|----|-----------------------------------------------------------------------------------------------------------------|-----|
| 13 | Liminality: a major category of the<br>experience of cancer illness<br>Commentary by Heather McKenzie           | 241 |
| 14 | Survivorship and discourses of identity<br>Commentaries by Phyllis Butow, Jane Cruikshank<br>and Samantha Miles | 264 |
| 15 | The skull beneath the skin<br>Commentary by Mira Crouch                                                         | 287 |
|    | Miles Little: a select bibliography                                                                             | 305 |

## Introduction

Ian Kerridge is Associate Professor of Bioethics and Director of the Centre for Values, Ethics and the Law in Medicine at the University of Sydney. He is also a Haematologist and Bone Marrow Transplant physician at Westmead Hospital, Sydney.

Chris Jordens is a lecturer and interdisciplinary researcher at the Centre for Values Ethics and the Law in Medicine at the University of Sydney. He has degrees in philosophy, public health and linguistics as applied to medicine.

Emma-Jane Sayers is a graduate in Asian Studies and Law and is Co-ordinator of the Survivorship Project at the Centre for Values, Ethics and the Law in medicine at the University of Sydney.

Miles Little is Emeritus Professor of Surgery at the University of Sydney. Born in Sydney, Australia in 1933, he trained at Royal Prince Alfred Hospital, and the University of Glasgow under Sir Andrew Kay. He was Senior Lecturer and Associate Professor in Surgery, University of Sydney, 1967-78 and Foundation Professor of Surgery at Westmead Hospital in Sydney, 1977-96. He was co-founder of the World Association of Hepatic, Pancreatic and Biliary Surgeons in 1987 and its first President from 1987-89. He became Founding Director of the Centre for Values, ethics and the Law in Medicine at the University of Sydney in 1995 and remained as Director until 2003. He has published over 300 journal articles in the medical, social science and philosophy literature. He is the author of two books on surgery of liver trauma and amputations, as well as a collection of poetry<sup>1</sup> and books on medical philosophy<sup>2</sup> and the experience of surviving cancer.<sup>3</sup>

The "Miles Little Reader" is a sample of papers from Little's later work which focus on medical philosophy, ethics and medical sociology. The papers in this collection were chosen by his readers, who also engage here with Little's work in a short commentary that follows each paper. The range of the commentators reflects the breadth of Little's appeal and influence: academics and clinicians, philosophers and ethicists, novelists, public health practitioners and cancer survivors – each reflects, agrees or disagrees. The papers are organised into three

sections which correspond to the major domains of Little's writing: ethics in medicine; philosophy and medicine; and illness experience and survivorship.

When browsing through a collection of papers by a single author, have you ever asked yourself: what sort of writer are they, what is it that characterizes their work? A quick glance at the titles of the papers in this collection would suggest that there is little point asking such questions of Miles Little's work. What do explorations of trust, evidence, epidemiology and cancer survival have in common? But as one begins to read Little's papers, the "ghost" of a philosophical methodology emerges.

Little's ethics are grounded in the sense of being tied to contingencies of experience, place, history and culture. He provides guidance by mapping the ethical domain. His work on resource allocation, for example, encourages some readers to re-examine the values of their own discipline, while his deliberate creation of a "discourse of survivorship" assists others to understand their experience of cancer survival in terms that do not medicalize or pathologize it. Little's ethics is also "post-Foucaultian" in the sense that it takes for granted sociological critiques of medical dominance, symbolic power, illness and social relationships.<sup>4</sup> His papers are also characterized by a series of common themes, including attention to humane values, virtues, relationships, narratives, discourse, language and meaning.<sup>2</sup> Finally, and perhaps most importantly, Little's work shares with Nussbaum an emphasis on ontology and the relationship to self, care, knowledge, community, security and human flourishing.<sup>5,6</sup>

But unlike other writers, who may be identified as utilitarians, virtue theorists, Christian ethicists or principlists, Little does not adhere to a meta-theory of ethics or align himself with a single normative framework. This is not to say that he rejects the value of outcomes, virtues or principles, but rather that his is a meta-ethical or axiological perspective and that he uses normative approaches as tools for *commencing* examination of issues or experiences and not as self-contained systems that would seek to close ethical discourse by providing a "solution".<sup>7,8</sup> Little's work is characterized by attention to the narrative, to the clinic, to history, to power, to language and discourse, to values and to community. It also questions modernist theories of knowledge that are based on a clear distinction between subject and object. Because of its "incredibility towards meta-narratives"<sup>9</sup> or global explanations, his writing is undeniably post-modern. Yet while it shares much in common with the work of Jürgen Habermas, Michel Foucault, Jean-François Lyotard and Jean Baudrillard, to simply label Little a "postmodernist" is to

misrepresent his philosophical approach and his methodology.<sup>10</sup> For while Little's papers reflect the postmodern attention to difference, discourse, language, power, politics and social context, his work also differs from the postmodern "traditions" in important ways. Whilst post-modernist and post-structuralist philosophers have widely rejected liberal humanism, Little's work can be seen as a kind of reconciliation project between the liberal humanist tradition and its modern, European arch-rivals.

As is the case with Lyotard, Bruner, Apel, Habermas and Rehag, Little's writing gives great emphasis to language, communication, discourse communities and narrative. Indeed the stress on narrative is a constant throughout Miles Little's work. For him narrative is dynamic, evolutionary, particularistic, emotional and explanatory and without an appreciation of narrative, progress in understanding any issue is unlikely to occur.<sup>9</sup> As he notes in "Assignments of meaning in epidemiology":

The various stakeholders often do not know each other's concerns and their genealogy. Logical argument and sustained reasoning will only work if they have a sound base from which to start. We are only likely to discover what our own perceptions are, let alone the perceptions of the other stakeholders, if we systematically generate and review the narratives within which we are consciously or unconsciously working.<sup>11</sup>

It is clear from Little's own research that he is finely attuned to the post-Wittgensteinian notion that communication is a deeply public activity and discourse provides the means by which we construct ourselves and the meaning that we assign to our own and to other people's lives.<sup>12</sup> Thus, his work attends to the perspectives, needs and aspirations of the "discussant", be they a doctor, a terminally ill person requesting euthanasia or a survivor of cancer, and also to the role that discourse communities have in medicine and in society. For, as is made clear from a series of the papers in this collection, Little believes that discourse communities are integral to our lives and that they express political and moral purposes. They give us a sense of belonging, they provide us with a means of communicating with others and they help us create our identities.

But while Little's work reflects the emphasis on discourse to be found in Habermas and Apel, and the emphasis on justice found in Rawls and Kant, his own work tends to be focused less on meta-theory or normative rigor and more on Aristotelian or Hegelian constructions of values, meaning, communication, community, respect and the "good" or the



"good life" (human flourishing). It also appears to allow space for poetry, dynamism, relationships, emotion and the unconscious and for the idea that language and discourse may be a source of subjectivity and culture as well as the result of it.<sup>13,14</sup> In this way his work is clinically richer and sociologically fuller than many other philosophers, and is closer to that of Wellmer, Foucault, Levinas, Deleuze and Benhabib. Little also appears not to share with Kohlberg, Piaget, Mead or Habermas a belief in "moral stages" in a logic of development or to presuppose a general theory of linguistic competence. Nor does he reduce language to a means of communication by instrumental interpretation or discourse to a tightly structured dialogue governed by discourse rules. Indeed, unlike Habermas, in particular, Little argues that dialogue is rarely unconstrained, that some voices may be absent or may have less power, that discourse communities may distort or restrict discourse, freedom or equity and that factors other than the force of argument may determine the outcome of any discourse.<sup>15,16</sup> In "Discourse communities and the discourse of experience" he writes:

The development of new discourse communities can serve positive ends, but discourse communities create risks as well. ... To be trapped within the discourse of a particular community is to put at risk the ability to communicate across discourses. Membership of a discourse community can impair the habit of critique, and deny opportunities for heteroglossic discourse. Privileging critique as a mode of discourse perhaps might define the ethical community, suggesting that ethical community may be an antidote to the constraining effects of conventional discourse community.<sup>17</sup>

Whilst he is committed to critique, Little avoids polemics because his aim is always to reconcile rather than entrench divisions. But for Little, neither discourse nor narrative are sufficient grounds for a moral life. It is ethics itself, rescued from the insularity of homogenous normative approaches — and it is the reflective, self-critical ethical community, that form the basis for humane society.

We can, therefore, articulate what sets Little's philosophy apart. But it is not only his philosophy that is distinctive, it is also his methodology. In his commentary in this volume, Paul McNeill makes the point that Miles Little's writing is stylistically transparent, accessible, emotionally engaging and deceptively simple. Each paper conveys complex ideas and draws from a wealth of literature without alienating or disenfranchising the reader. In part this is because Little's work presumes that ethical analysis requires identification of, and attention to, all major stakeholders and also because it favours attention to detail, context and

meaning. But the fundamental reason that these papers demand our attention is because Little's methods enable us to understand the situations he presents to us. His approach to research is deeply hermeneutic or phenomenological, often using specific exempla, experiences or narratives as a means for generating truths about moral philosophy, medicine and the lived experience. Like poetry, these forms of inquiry engage the reader on a deep and personal level, bridge the gap between individual experience and the human condition, and help us to understand the ordinary, the unexpected and the ineffable elements of human experience in health and illness.<sup>18</sup> When we read Miles Little's writing we understand the situations he presents us and we are helped to understand them better.<sup>19</sup> When Little writes of the experience of cancer: "extreme experience is extreme because it leaves no aspect of identity untouched" we have a sense of the existential upheaval of survival following life-threatening illness and feel something touch our own sense of mortality.<sup>20</sup>

But, as a number of the commentators in this collection note, while Little's writing is engaging, and accessible, his papers are also challenging. They challenge the reader, they challenge accepted maxims and they challenge accepted dogma; about euthanasia, about health economics, about consent, about evidence in medicine and about the experience of illness. Little emphatically rejects positivism, instrumental thinking and Cartesian models of the mind-body dichotomy. He also rejects the idea that the law, science, economics, discourse or epidemiology can "solve" complex moral problems and instead suggests that uncertainty and complexity are consistent features of medicine, of ethics and of society. Indeed if the reader of this collection hopes to find solutions or definitive conclusions they will be disappointed for Little's papers rarely provide solutions. They "conclude" instead with a series of questions, or a call for reflection, re-evaluation or "valuation".

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## Part 1

# Ethics in medicine

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## Commentary

Alison Moore is Research Co-ordinator at the Centre for Language in Social Life in the Department of Linguistics, Macquarie University. She specializes in the discourse of medicine and other contexts of care. Jason Grossman is a lecturer in the Unit for History and Philosophy of Science at the University of Sydney, and specializes in the philosophy of statistics.

Miles Little contends that the problem of communication between the various users of epidemiological analyses is a manifestation of a more general problem, noted by a number of philosophers since the 1960s, that there are many ways of explaining any phenomenon, each of which looks like – but isn't – the explanation of the phenomenon. Little says (and we agree) that epidemiologists are particularly susceptible to this problem, and he prescribes a dose of narrative explanation, adjuvant to their numerical explanations, as the best prophylaxis.

Most importantly, health inequalities won't be best addressed by large quantitative studies, says Little: "Purer science, larger series and more refined analysis guarantee neither more meaning nor explanations that are more comprehensible".<sup>1</sup> A recent paper<sup>2</sup> illustrates this well. The authors demonstrate that it is often necessary to take data in narrative form, and focus on health problems that lie below the threshold of what usually worries epidemiologists (e.g. gynaecological problems), in order to understand the complex causal networks of more epidemiologically explosive issues such as HIV, and understand how the burden of ill health is really distributed.

Williams<sup>3</sup> has also noted that epidemiology needs to take more notice of people's narrative accounts of cause and effect relationships between social life and health, arguing that lay explanations often incorporate structural accounts of interest to epidemiologists and policy makers: "Until money is spent on these areas [i.e. deprived residential areas] ... there doesn't seem to be much point in trying to stop people smoking and what else. As long as the environment is going down the pan the people will go down with it", says one of Williams's perspicacious research subjects. This work was discussed at a recent colloquium<sup>4</sup> as the "new" idea of bringing narrative and epidemiology together. We note that Little was there some time ago.

But before we pick up Little's ball and run with it, we need clarification of where he is heading. The final sentence in his paper reads:

"Translation of findings into narrative is likely to do more to achieve wider meaning available to those in search of it". We think this is possibly misleading. In our opinion, the issue is *not* that epidemiologists should do the work that they were going to do anyway and then translate it into a different language. Instead, they should *contextualize* their work within social and linguistic frameworks that are constructed — partly — from other people's narratives.

Since social views of the world are often contentious (especially when discussed in postmodernist language, as they so often are), we suggest that the best way to make our proposal palatable to the epidemiological community is to increase the extent to which epidemiologists discuss the *political* aspects of their work. Thinking politically can easily lead to thinking sociologically.<sup>5</sup> Little seems to agree with the points we are making. First of all, when he says that we need to do stakeholder analysis before we start doing epidemiology, he seems to be concurring with our view that merely translating narratives for different audiences is not enough to achieve what he's after. And secondly, he suggests "that epidemiology may need to ... expand its conceptual horizons to include the values which ground the whole health endeavour in modern, western countries".

What Little is really interested in, we suspect, is not translation, nor is it limited to narrative. He is interested firstly in incorporating the points of view of a variety of stakeholders into epidemiological studies; and secondly, he is interested in understanding the *latent patterning* of meanings in all sorts of genres through which such points of view are constructed, reflected and mediated. For example, we have been finding it useful to analyse the linguistic patternings that position people and things as agents (entities with control over the future). Although it has been important to explore the role of narrative in construing agency and identity (as has Little<sup>1</sup> and other scholars such as Bruner, Nussbaum, Lyotard, who he cites), narrative is by no means unique in this, and the dramatic "emplotment" that narrative produces is but one level of linguistic patterning which can foreground, obscure, and problematize agency. Many patterns of meaning — grammatical, semantic, visual, proxemic and architectural — interact to position social actors.<sup>7,8</sup>

The experience of HIV and Hepatitis C provide useful examples here. People Living with HIV/AIDS (PLWHA) in western countries are thought to take a particularly active role in medical decision making, and have high rates of treatment adherence. These phenomena are probably related.<sup>9-12</sup> The way in which PLWHA construct their own agency (and the agency of others) in narrative genres provides insights about which

treatment choices<sup>13</sup> and risk practices<sup>14</sup> are acceptable and why. In not-so-narrative modes of discourse, such as treatment consultations, HIV patients who are *represented* linguistically by themselves and doctors as active collaborators in decision making, also tend to *enact* a more active role, e.g. "I'd rather not play around with these treatments that we don't know much about".<sup>15</sup> In expository discourse, such as editorials in medical journals, HIV patients are typically construed as active in the treatment and prevention of infection, whereas patients with HCV are construed as donors of contaminated blood and transmitters of disease — but *not* as agents of any positively valued action.<sup>16</sup> Editorials conflate agency and blame in people with Hepatitis C, despite their own focus on community responsibility when discussing risk practices.<sup>17</sup>

How might such representational differences relate to epidemiology and clinical care in HCV and HIV? We know that prevention has been less successful for HCV than for HIV; that HCV patients report abusive treatment from health care workers and despair of ever changing this;<sup>18</sup> and that harm minimisation remains a political nightmare compared to vaccinations and combination therapy, despite the considerable stakeholder analysis that epidemiologists in both fields have undertaken in the way that Little suggests.

Clearly there are no easy solutions. But it seems likely that mapping differences in how people are positioned by different modes of discourse (editorial, illness narrative etc.) and fields of discourse (HIV, HCV etc.) will help clarify the extent to which different health stakeholders can talk with each other in the same terms about the same thing.<sup>19</sup> In our view, making and defending such comparisons requires a multi-dimensional, functional account of language to complement narratology. The scope for bringing such analyses to bear on epidemiological approaches to inequality is relatively uncharted. It will depend in part on whether *linguists* can look beyond disciplinary habits, as Miles Little is asking *epidemiologists* to do in his provocative paper.

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## 6.

# "Better than numbers ..." A gentle critique of evidence-based medicine

By Miles Little

## Abstract

Evidence-based medicine (EBM) has achieved cult status in the last ten years or so. It is an altogether admirable movement in medicine, capable of a great deal of good. Its privileged status, however, has prevented critics from being heard, and there are problems with EBM. Eight features need further discussion if EBM is not to be discredited and superseded. They are its reductionism; its unwitting paternalism; its privileging of restricted kinds of evidence; its dependence on the questionable concept of equipoise; the instability of the "truths" it produces; its capacity to eliminate individuals in favour of categories; its historical arrogance; and its contempt for the wisdom and integrity of our predecessors. Evidence-based medicine is here to stay — for the moment, at least. It is sufficiently well established to withstand critique. It needs criticism if it is to survive and flourish.

## Introduction

A few honest men are better than numbers.

*Oliver Cromwell (1643). Letter to Sir William Spring*

Evidence-based medicine (EBM) has become the fashionable rallying cry of the modern age in medical education and clinical research. It has achieved this status because it promises something good, the ultimate benefit of patients, their rescue from the uncertainties of tradition and unsupported authority. EBM appeals to "gold-standard" evidence, the results of randomised controlled trials (RCT) and meta-analyses in order