

REVIEWS

Scalpel medical ethics.

Special issue of *Humanscape* 1997;4:1-42

Focussing on a broad range of topics, this journal has striven to uphold standards and highlighted fearlessly our existing deficiencies.

The special issue on medical ethics is edited by Dr. Amar Jesani. The essays on this subject occupy 33 of the 42 pages and include analysis of euthanasia (Kannamma S. Raman), organ transplantation (Sanjay Nagral) and the facilities provided for health care in the public sector (Rashmi Lakshminarayana). The latter essay brings out forcefully the declining interest shown by the central government and those in most of our states in providing for the health and treatment of our poorest citizens. The table showing the availability of dispensaries and health centres in our states is especially revealing. Kerala is the only state where 90% of villages have a dispensary within two kilometres and 47% have a health centre in the same range. Contrast the figures for a state such as Maharashtra, where our rulers claim that they are enlightened. Dispensaries are available within two kilometres to just 22.3% of villages and health centres in the same distance to just 7% of villages! It is a matter of considerable surprise that corresponding figures for Bihar are 25% and 3 1%. The data analysed in this essay demands careful study and corrective action.

Rama Baru discusses 'philanthropy for profit' - an apt title for an essay dealing with our private and 'charitable' hospitals. Whilst no one grudges the need for private hospitals to make a profit, when this is done after availing themselves of tax concessions on the basis of professed concern for the poor and through the misuse of the same high technology equipment thus imported, the failure of our regulatory agencies becomes especially worrying. Take this essay together with that by Sunil Kaul ('If one were to attempt a classification of quacks, it may be well to start with senior professors...') and you are made well aware of the lack both of rationality and ethics in medical practice.

Is the solution proposed by Thomas George (eliminate the profit motive and stop private practice) feasible?

The closing section provides two accounts by the relatives of patients of their experiences with doctors. In both instances medical negligence has been alleged, Navin Shah, settled in USA, discusses the

role of litigation.

It is a pity that the last page, entitled *Human Index*, has not been exclusively devoted to facts from Indian medicine. These would have proved especially effective in underlining the contents of many of the preceding essays.

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The gravest show on earth: America in the age of AIDS. Burkett Elinor, Houghton Mifflin Company, Boston. 1995. 399 pages.

(This book is available at the library of the American Center, Mumbai. 362.1969792/BUR)

Introduction

This is an extraordinary account of the evolution of our understanding of the disease produced by the virus that destroys immunity in humans. It contains the fruits of seven years of research on the subject. For anyone interested in learning the truth on this disease, this is a book that must be read.

You will get some idea of the quality of what is on offer from the first and second paragraphs under 'Acknowledgements':

"No individual ever authors a book alone. Books, like ideas in them, reflect a complex series of interactions, relationships and experiences that form a unique consciousness.

"Three of the individuals whose influence is stamped most heavily on this work are dead. Enrique, Juan and Miguel shared their deaths with me. In doing so, they offered me the profound gift of a series of lessons in fear, pain and morality, as well as the courage and grace about which so much is written. Mostly they taught me about honesty -- for when your life is narrowing to fewer and fewer weeks, and to increasingly confined spaces, truth emerges from the ruins of banality with extraordinary clarity. If I no longer mince words, it is because I have learned, in the most profound way, that there simply isn't any lime."

Truth - sacrificed to other interests

Burkett shows how easily truth becomes a casualty of competing interests; commercial, political and scientific. She provides details on several individuals. The story of Larry Kramer -- novelist and

playwright, fund-raiser for those suffering from AIDS and self-appointed conscience-keeper with a genius for converting friends into opponents -- is fascinating.

Her narrative of the 'discovery' of the AIDS virus by Robert Gallo -- championed by American media and politicians -- and demonstration of how credit was snatched away from the true hero, Luc Montagnier of France, by Gallo; is just one of the fascinating glimpses offered by her of what went on behind-the-scenes. She also describes how Jonas Salk (of the vaccine fame) provided incomplete information on his own researches on HIV in such a manner that his company's stock prices kept moving upwards.

She tells of how Henry Heimlich (famed for his maneuver to free the airway of an ingested obstructing agent) touted the malarial plasmodium as a cure. She weaves the different threads of her narrative deftly and effectively.

Transmision of HIV virus from dentist to patient

The story of Kimberly Bergalis (in Chapter Eight entitled *The immaculate transmission*) is especially stomach turning. This girl, who was a virgin, had never used drugs or received a blood transfusion, when she developed AIDS. The infection was eventually traced to the removal of two of her teeth by Dr. David Acer, a homosexual dentist, two years earlier. Acer tested positive for HIV and developed AIDS. Even after this information became public knowledge, reporters continued to ask whether her hymen was intact and whether there was proof that she had never had anal penetration. Others called her a slut and worse. On her death from AIDS, her parents were sent obnoxious letters, one of them stating: 'Thank God the bitch is dead. She got what was coming to her.'

Capitalising on AIDS

The chapters dealing with the 'AIDS gravy train' shock the reader in the manner that the author fully intended. That individuals -- including scientists -- and corporations should do everything in their power to profit from the AIDS industry leaves us numb. Consider just some of the spheres which have spawned venality: researchers flying from one conference to another -- almost always in five-star hotels in exotic locations, the biotechnology and pharmaceutical trades, manufacturers of condoms and other such accessories, AIDS and bereavement counselors, AIDS spokespersons and activists heading large

organisations.

The book is amply documented. The section listing and describing her sources covers twenty-two pages.

Conclusion

If you look for sentimentality in this book, you will be disappointed. If, however, you are searching for the facts behind the masks, camouflages and cover-ups, you've opened the correct volume.

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Diagnosis of Occupational Diseases. Eds: Murlidhar V, Vijay Kanhere, New Delhi: Society for Participatory Research in Asia (PRIA). 1996.

Impairments, Disabilities and their assessment. Eds: Murlidhar Veena, Murlidhar V, Kanhere Vijay, New Delhi: Society for Participatory Research in Asia (PRIA). 1996.

A few years ago on a visit to the Western Coalfields Hospital at Chandrapur I was asked to demonstrate upper gastrointestinal endoscopies on patients at the hospital, all of whom were coal miners. I was surprised to find a large number of these patients suffering from severe gastritis and peptic ulcers and naturally wondered whether their exposure to coal dust could in anyway be responsible for this. I inquired with the local doctors who confirmed the high incidence of these diseases but were themselves not sure whether this could be related to their occupation. I realized how poorly equipped and trained we were as medical professional to identify possible occupational sources of disease and I am sure all of us from whichever field of medicine encounter such situations in our practice. In a sense this is a failure on our part to sensitize ourselves to a very important aspect of our patients' problems which has major social, legal and financial implications

It is against this background that the above books written by doctors and health activists who are not full time occupational health practitioners, but are working voluntarily in the field, form an important contribution to an area in which there is very little written in proportion to the problem in India.

Published by PRIA, a Delhi based NGO working in the field of occupational health for the last decade, these books have been compiled after consulting a number of experts from various fields

including teaching hospitals in the metros.

The first book takes the list of occupational diseases mentioned under schedule III of the Workmen's Compensation Act (1923) as it's basic structure. Each disease is then dealt with in brief under the headings 'Industrial Occurrence', 'Signs and Symptoms' and 'Diagnosis'. The information is presented in simple language and can serve as a ready reckoner for any practicing doctor. For example as someone interested in liver disease I often see patients with non-cirrhotic portal fibrosis of the liver which has been described in association with arsenic contamination of water. But the book mentions a lot of common vocations in which there is chronic exposure to arsenic and one wonders whether the link with arsenic could be occupational. The list of possible occupational cancers is indeed frightening and one wonders whether all the money that is being put into cancer treatment is better utilized for preventive purposes. To illustrate their point the authors also sporadically present case reports of patients seen by them in the Occupational Health and Safety Centre, Mumbai a place where the authors actually give free medical and legal help to victims of occupational disease. One does however feel the absence of appropriate photographs which would have been very useful to appreciate some of the lesions described.

The concepts of 'impairment' (a purely medical definition) and 'disability' (a medical and legal definition) are often related by medical professionals only to limb loss or loss of special senses. The second book which is slightly more technical is a compilation of guidelines to assess disability and impairment covering almost all the body systems. It's strength lies in the guidelines it provides to quantify impairment in situations like splenectomy, bladder and bowel disorders, endocrine disturbances and others. The book also gives formulae to combine impairment of various body systems so as to give a total impairment figure. It is full of case reports which especially exemplify the methods of combining impairment percentages. The book has a large number of Tables which, although relevant, occupy a lot of space. What is not very clear is whether if a practitioner decides to use the guidelines in this book to quantify impairment it would be legally acceptable to employers and courts.

Occupational diseases often affect poorer sections of society from the working class especially those in the unorganised sector. Also, occupational health is an area of

health care which is neglected by the state, the medical profession, as well unfortunately also by workers organizations including trade unions. A classic example of this is the total state of disarray of the Employees State Insurance Scheme (ESIS) in the state of Maharashtra. The challenge therefore lies in actually stimulating the medical profession to play a more pro-active role by utilizing the knowledge available in such books in their day to day practice. In a larger sense this means looking at the patient's problems as those arising from multiple factors including his or her workplace and not just in the narrow confines of disease—specific etiology that modern medicine often tends to emphasize. One way of achieving this could be to lay greater emphasis on subjects like occupational health in the undergraduate curriculum as well as establish more postgraduate courses in this field. In addition, recording and notification of occupational diseases could be made mandatory and books like these be made accessible to practitioners as ready reckoners. But ultimately the pressure will have to come from workers and their organizations who through struggles, litigation and campaigns will have to sensitize the state, the employers as well as the medical profession.

The authors of these books have made a small beginning not only by compiling this information but also for the first time successfully getting compensation for a victim of Byssinosis, a textile worker in Mumbai. For those in preventive medicine, occupational health is one of the most important areas for intervention. And for those who take a broad view of medical ethics to encompass social ethics this is an issue that once again emphasizes the social origins of ill health and disease. As the authors quote Henry Kessler in their introduction to the second book;

"What is man?" the Bible asks.
"A machine", the engineer replies "subject to the laws of thermodynamics"
"A voter", the politician answers
"A worker", the economist proclaims.
"A patient", says the doctor. (my addition)

But the poet says, "Man is not an economic entity, nor a statistical cipher. A man's a man, with a mind that can perceive the truth, with a heart that understands love and beauty, with eyes that can behold the glories of the sunset and cheeks that can feel the gentle winds of morning."

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Oh, for a little humanity in doctors!

Not many laughs this last fortnight. I went to visit a close friend in a hospital near London who had recently had a breast lump and her lymph glands removed. I found her curled like a foetus on her bed in one of those grim wards that seem positively designed to make you feel ill.

I was shocked by how utterly drained and beaten she looked. She had been home since the operation and had sounded quite perky on the telephone. Yet after being in this hospital for only a couple of days she looked finished.

Physically, it transpired, she was feeling not too bad; emotionally she was wrecked. Two days before, still weak from the operation, she had been invited to turn up at 10.00 a.m. to learn the results of a scan. She waited all day. At 6.00 p.m. she was told that she had cancer of the liver and four small brain tumours. She seemed to have no idea what the treatment would be, whether it was worth having, what her options were, where she would have it, what the effects might be. To just about all of the hundred and one questions I asked her, she said: "I don't know."

"Haven't you asked the doctor?" I kept saying. Oh, she had tried. But he was so dry, so distant, always in such a hurry. It wasn't that he was rude, exactly, just that he never looked her in the eye, never seemed to speak directly to her, just barked questions at the nurse over her head, and grunted in reply.

"I kept trying to focus on the right question, but the next minute he was gone. In and out like a whirlwind. It happens every time I see him. I get so confused. He flusters me. Nothing comes out right. I think he's taken one look at that scan and consigned me to the scrap heap. Three people have died in this ward since I got here. All I can think about is whether I'm going to wake up tomorrow.

"Am I going to wake up tomorrow?"

Who was this man who called himself a healer yet could so effortlessly turn an illness into a trauma and so casually crush a fragile spirit long before the body had done its worst? Do doctors like him have no imagination? Has familiarity with illness and fearfulness bred something worse than contempt? Has it atrophied their very humanity?

What had this man done? He'd done nothing. Precisely nothing. I honestly don't believe it would have ruined his schedule to treat her as an individual rather than the next in a line of diseased flesh, and encourage her to ask some of the questions he must have known were crowding into her mind. A couple of minutes spent looking directly at her, touching her hand maybe, goodness, even perching on the end of her bed, would have prompted her to burst out with the big question haunting her most: "Will I die tomorrow?"

Into the valley of the shadow of death: Sally Magnusson

British Medical Journal Volume 313, 21-28 December 1996

Announcement

We learn from the newsletter of the Society for Scientific Values (New Delhi) of two interesting new books on ethics in science:

Kapur IN: *Ethical values for excellence in education*. New Delhi: Wiley Eastern Ltd. 1996

Professor Kapur's book deals with moral values vital for excellence in science, education and society.

National Academy of Sciences: *On being a scientist*. Washington DC: National Academy of Sciences 1995.

Whilst this book is primarily aimed at teachers and researchers in USA, the principles enunciated are of universal importance.