

Book reviews

Humane care for the Alzheimer patient

F. Gray-Davidson, *The Alzheimer's Sourcebook for Caregivers*, Lowell House, Los Angeles (1999). 276 pp. ISBN 0-7373-0131-7. 1999. US\$ 16.95.

The subtitle of this book is “Getting through the Day”. That could suggest to the potential buyer scanning it in a bookshop that it is primarily a volume about how the caregiver himself or herself, entrusted with the care of an Alzheimer patient, gets through the difficulties and disappointments of the every succeeding day. That is in fact only half the author's intention; it is an intensely humane book about how to care for the Alzheimer patient in a manner which respects the patient's rights and dignity, as well as providing the basic essentials of physical support. In that respect it is as instructive for the professional caregiver as it is for the family faced with the day-to-day problems of handling a loved one with whom one largely seems to have lost contact forever, and where there is no real prospect of alleviation. It also provides a thoughtful guidance about the difficult time when it may be necessary to arrange for the patient to move to a nursing home, a phase which may be traumatic for the family and intensely confusing for the patient.

Communication is a recurrent theme: it is always very possible that a patient with Alzheimer's disease is aware of a great deal more, and undergoes far more emotional turmoil than his or her speech or behaviour would suggest. There are means of taking up again to some degree the lost threads of contact, though they demand time and patience, items which the family may be better able to supply than even the best and most adequately staffed nursing home. But as one lay caregiver cited in this book describes the family's problem: “No one tells you what to do for the best. Doctor's don't seem to know. Leastways, ours didn't. People like us don't know about this thing, and it's real hard to find out. . .”

Gray-Davidson's book is one way of getting both help and reassurance. It deserves to be very widely used.

The children's crisis

Peter R. Breggin, *Reclaiming our Children*, Perseus Books, Cambridge, MA (2000). 340 pp. ISBN 0-7382-0252-5. Price not stated.

Peter Breggin is perhaps most familiar to readers of this *Journal* as one of the most outspoken and critical voices in the debate around the massive use of stimulants to treat the so-called “Attention Deficit Hyperactivity Disorder” in America's children. But there is a great deal more than that to his work as a psychiatrist who found his mission in building a better understanding of the mental needs of children. He has rightly been called “the conscience of American psychiatry”, and even those who reject some of his views have learned to respect the compassion and the concern which underlie them.

This book was largely inspired by a series of incidents of child violence, particularly the killings at schools in Littleton, Colorado and at Conyers, Georgia in 1999. For many these tragedies sparked an

urgent desire to tackle the problems of America's children, but it is a desire which in some respects has led to serious misjudgements as to what is wrong and what ought to be done. In particular, it seems to have catalysed the belief that a great many children are suffering from mental problems of biological origin, that they must be actively identified and given psychiatric support, and that this support will in many cases involve administering drugs. Breggin himself is quick to point out that at least two of the high school killers in Littleton and Conyers were already receiving psychiatric care – and killed while under the influence of the drugs that had been prescribed for them. The problem of America's children, as he delineates it, is a far broader one: "All our children are at risk. . . They are endangered by a plethora of stressors, from alienation at home to peer humiliation at school to drug and alcohol abuse to precocious sex to gun-related accidents to car crashes. . . No parent or caregiver can afford to assume that one or another child is invulnerable." His list of stressors is in fact much longer, including isolation induced by computer games and intensive television watching, the loading of domestic responsibilities onto young shoulders, and an educational system which places an excessive emphasis on grades and other tangible signs of success at school. None of these things are exclusively American: they are growing in every industrialized and urban environment and often beyond. Peter Breggin's study is not going to arrest them or solve them, but it is an important first step to understanding them, and in pulling away from ill-chosen "correctives" which may do much more harm than good.

Hospital infections

E. Schmidt, *Le Risque Médicamenteux Nosocomial*, Masson, Paris, (1999). ISBN 2.225-83587-X, 288 pp. Price not stated.

Hospital infections – whether incidental or of epidemic proportions – are a universal problem of a type which is in essence very largely preventable. It is becoming a disaster in terms both of public health and of cost. Étienne Schmidt has provided a massive overview of the challenge, its causes and approaches to a solution, covering not only his native France but (on the basis of a broad literature review) the world as a whole. It is backed by detailed figures.

The roots of nosocomial infection lie in the intensive use of antibiotic drugs in the hospital, a closed environment within which organisms which acquire resistance can all too easily find a long-term home; within that environment they can readily infect patients, transfer their resistance to other bacteria, and comprise a source from which resistance can spread out into the hospital's catchment area.

That antibiotics are intensively used in hospital is unavoidable; the fact that they may be excessively and even recklessly used is not. Where use has been constrained, there are plenty of pointers to show that nosocomial infections fall dramatically. Changing prescribing habits in the hospital environment is however more easily proclaimed as an ideal than put into practice. Senior consultants are commonly the prescribers least ready to learn and adapt; juniors follow the role of seniors, and may tend to prescribe a little too much for rather too long in order to demonstrate that they have been assiduous; the nursing staff is rarely in a situation where it can raise a challenge; and the hospital pharmacist, in theory well placed to take action, can only be as successful as the degree of inter-professional respect allows.

Schmidt is not a pessimist, but he is a realist who sketches the magnitude of the difficulties to be overcome, as well as indicating the road ahead. This is a splendid study; and even for those who are not fluent in French, the tables and the wide ranging literature references provide an important collection of facts.

Lessons from Bangla Desh

Z. Chowdhury, *The Politics of Essential Drugs*, University Press, Dakha. ISBN 984-05-1320-6. 174 pp. Price not stated.

This is not a new book, but it is one which only very recently has been taken into the list of a western publisher and more widely disseminated. Essentially it is built around the history of the spectacular drug policy which Bangla Desh introduced in 1982, and which during the ensuing decade was effectively sabotaged by the multinational pharmaceutical industry, largely through its manipulation of politicians. The country, one of the poorest on earth, had set out to provide its peoples with low-cost drugs, effectively shedding the burden of contributing to the profits and research investments of the global pharmaceutical industry. It could have resulted in spectacular gains for public health; instead it sparked a conflict and controversy in which the politicians – including the U.S. State Department – played a less than edifying role. As a chronicle of a battle which was lost – but which deserves to be remembered as a lesson to health policy makers everywhere – this little book is invaluable.

M.N.G. Dukes

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Informed consent

H. Leino-Kilpi, M. Välimäki M. Arndt et al., *Patient's Autonomy, Privacy and Informed Consent. Biomedical and Health Research Series*, Vol. 40. IOS Press, Amsterdam, Berlin and Oxford. ISBN 1 58603 039 6, 2000, 176 pp. NLG 160/EUR 72.60/US\$ 74/ 46/DM 142.

Informed consent is a splendid principle, but it always runs the risk of also being a splendid fiction.

The traditional concept of the physician decreeing what shall happen to the patient, complemented by humble acceptance on the part of the latter, is supposed to be dead. Instead one is supposed to attain a situation in which the physician consults with the patient on the treatment to be administered, providing him or her with all the facts necessary to take a decision, after which the treatment is instituted by mutual agreement. The difficulties with attaining this ideal are all too evident. It requires both parties to participate fully, a condition which the doctor may fail to meet and which the patient may not even desire to accept. A lot of patients certainly continue to see the physician as standing on his traditional pedestal, learned and perhaps unapproachable, and are only too anxious to have their treatment dictated to them. Some do not feel capable of participating in the decision. Some, particularly minors and the mentally impaired, may simply not be capable of doing so. These things are barriers to true patient autonomy. The process also puts considerable demands on the doctor; a lot of prescribers work under constant constraints of time, and both informing the patient adequately and conducting a proper-discussion demand time; one recalls visits to some clinics in developing countries where the entire process of diagnosis and prescription has to be completed in two minutes or less. Even where the time can be found, the right means has to be found to impart information without at the same time exerting undue influence (and can one define what sort of influence is “undue”?).

This extensive literature study by Leino-Kilpi and others forms part of the European BIOMED2 project, funded by the European Commission and based in five countries. While it provides a thorough and readable overview of the literature on patient autonomy, privacy and informed consent, it also seeks

to identify data on the way these concepts function (or could function) in three specific situations: that of mothers with infants or babies in post-natal wards, that of surgical patients in hospital wards, and that of long-term elderly patients in care institutions. Mothers who are having a baby represent a "healthy" group, a cross section of younger adults, who are likely to be highly motivated to participate actively in the decision-taking, especially where the baby is concerned. Surgical patients raise a series of questions regarding information on both surgery and anaesthesia as well as the problem raised by unconsciousness, during which their physical integrity may be violated by health care personnel. The elderly in long-term care are a classic case of patients who find themselves in a heavily dependent situation in which all decisions may in fact be taken by others.

The literature cited in this book raises a series of problems which go beyond those summarized above and which demand attention. One is clearly the fact that even committed physicians commonly overestimate the extent to which they have given information and the extent to which the patient has understood it. The difficulty may lie in the content and language of information or in the way it is presented. In some way these are matters which are going to have to find a place in the already over-stretched training programmes of professionals, and in the supervision of the newly qualified practitioner and nurse. Consent forms, such as those used for hospital admission and surgical operations, need to be made simpler and they also need to be explained verbally before they are signed. In work concerning nursing homes for the elderly, the importance of dress has come to the fore as a means of preserving the inmate's personality, identity and uniqueness so that he or she remains an autonomous individual – to be respected and listened to – rather than a mere number with an allocated bed.

As a European study with plenty of global input, this volume necessarily runs into intercultural differences. Patient autonomy and informed consent have developed further and faster in some countries than others, with Scandinavia attaining perhaps the most enlightened situation of all.

Ethnicity has been found to play a major role related to attitudes regarding truth-telling and patient decision-making. Korean Americans and Mexican Americans proved to be significantly less likely than European Americans and Mexican Americans to believe that a patient should be told the diagnosis of metastatic cancer. Nurses in Australia, Canada and Sweden most often chose not to provide assistance in feeding demented patients, while nurses in Arizona, California, Finland and Israel often chose to feed the demented patient as a matter of priority. Canadian surgery patients were more positive than Scots in their desire for information on anaesthesia.

This is an useful repository of information on the three related topics which it seeks to cover, but it is not an easy book to read nor is it a volume which provides much guidance. The student of any of these areas will find here a well-arranged overview of what has been done and written but there is relatively little discussion and the authors could have gone further in indicating on which topics evidence is conflicting or further research is needed. Bearing in mind that this is an initiative of the European Commission one could have expected more in the way of proposals for European standards. The problem may have been that the bulk of the eleven authors were social researchers, many with nursing qualifications but not with medical training. The project as a whole will however continue into 2001 and it may be hoped that more critical analysis is and delineation of acceptable and realistic guidelines will be feasible within that period.