

International child health care: a practical manual for hospitals worldwide

Edited by David Southall, Brian Coulter, Christiane Ronald, Sue Nicholson, & Simon Parke
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This large book (626 big pages) takes on an ambitious, arguably impossible, task. It aims to be a comprehensive text for paediatricians in hospitals worldwide: to be a resource (according to the forward) for 'big teaching hospitals', rural hospitals, and village clinics, in emergency and 'chronic' situations, in 'peace and war'. The way in which the authors succeed in some areas and fail in others highlights the difficulty of providing guidelines for paediatric care that are applicable to all situations.

There are many very good chapters. Those on meningitis, orthopaedic conditions and acute diarrhoea provide concise guidelines and appropriate treatment options for settings with varying resources. The chapter on epilepsy outlines an overall approach that could be applied in developing countries, despite gaps in the section on febrile seizures. The chapters on palliative care and grief and loss in war-affected societies are truly needed sensitive approaches to these common and difficult problems for children in the world today.

Failures in other areas highlight the need for a balance between interventions that are affordable and effective in wealthy countries, and the realities and priorities for poor countries. The notion of 'resource steal' is crucial for putting the book into perspective. For example, building up a centre for specialized cardiac or intensive care services (both proposed as theoretical 'minimal standards') might steal essential human and financial resources from primary rural or basic referral level hospital care. Neonatal incubators are recommended but there is no balancing argument outlining their disadvantages in developing countries; "kangaroo" care is only briefly mentioned ("where incubators are not available") and other low-cost alternatives such as "warm-room" care are largely ignored.

The book could be seen as having two main themes: one a philosophy

of care, and the other the technical aspects of paediatric medicine and nursing. The thesis is that much of the technical requirement for care should somehow be based on 12 philosophical standards of care, as defined by the Child Friendly Hospital Initiative of Child Advocacy International. These 12 standards are in turn based on the UN Convention of the Rights of the Child. The principle is that sick children everywhere deserve a certain standard of care. The editors are staff from Child Advocacy International, a UK non-governmental organization that aims to assist health workers in poor countries to improve hospital care for children.

This combination of moral and technical concerns does not always work very well. Some of the recommendations lack sufficient scientific evidence or do not take account of the extreme resource limitations of many developing countries. The book states, for example, that 'ultrasound equipment should be available in every institution that merits the title of Hospital', and that non-invasive respiratory support constitutes a minimal standard of care for acute respiratory infections. In reality, though, a hospital is better judged by patient outcomes than by its equipment.

Negative pressure ventilation is recommended for acute lower respiratory infection, but even in resource-rich neonatal intensive care units this procedure has proved difficult, expensive and potentially hazardous. In a serious approach to evidence-based paediatric care, negative pressure ventilation might be suggested as an option for post-operative respiratory support for children with a Fontan circulation and for home ventilation of children with chronic neuromuscular disease, not for pneumonia in developing countries. Instead, it would have been better to describe the least expensive ways to deliver oxygen. Once oxygen supplies are guaranteed, clearer detail could be given on a practical method to make and use a simple CPAP circuit in level 2 or 3 hospitals.

Although the book advocates appropriate technology, there are many messages about the superiority of high technology equipment and drugs. It needs to be emphasized that in many cases appropriate technology is not inferior; it is simpler, makes more

efficient use of resources, and is more robust. There is too little recognition that complex technology is harmful if staff are not able to use it properly.

It is not always clear when the authors believe that the "Minimum Standard Requirements" highlighted in the shaded boxes at the start of each chapter represent what should be available in *every* hospital, in secondary hospitals, or in one tertiary referral hospital within the country. Also the implied link between these and human rights is tenuous.

As is common in multi-authored books, some of the recommendations are contradictory. For example, age-appropriate respiratory rates and those that indicate respiratory distress, and dosing intervals for gentamicin differ in different chapters. Recommendations on the use of intracardiac drugs for neonatal resuscitation conflict with those of the Neonatal Resuscitation Program of the American Academy of Pediatrics, whose programme is promoted in a separate chapter on self-instructional courses in neonatal resuscitation. Some statements show an incomplete grasp of the existing evidence, others are wrong, poorly worded or inappropriate (examples can be given on request; I do not have room to cite them here). The diagnostic algorithms are difficult to follow with floating boxes and missing arrows, and some lack perspective: a health worker following the difficult breathing algorithm would need to consider volatile substance inhalation, and organophosphorous poisoning, before considering pneumonia.

Having said all that, much can be learnt from this book. Many of the chapters are well written and contain excellent condensed technical information that has not been presented before. Perhaps the most important thing this book makes clear is that reliable up-to-date, low-cost, evidence-based guidelines for paediatric care in hospitals in developing countries are urgently needed, but they have to reflect an appropriately balanced use of resources. They also need to target specific settings of care, to emphasize low-cost simple technology options and drugs, and to be sensitive to the efforts of health workers. Furthermore, they need to consist of the strongest evidence available, and either to be peer-reviewed internationally or endorsed by the consensus of experts

consisting predominantly of doctors and nurses from resource-poor settings. Other recently published manuals and some older texts come closer to meeting these requirements. ■

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Work and unseen chronic illness

Margaret Vickers
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Margaret Vickers's research is on how people live with chronic illness, and how they deal with the mistreatment such illness incurs at the workplace. As an academic with multiple sclerosis (MS), she has firsthand knowledge of this subject, and makes effective use of it. She also uses the experience of her husband, who is suffering from sarcoidosis, and of how their illnesses affect their relationship.

Her main research material, however, is the texts of extended one-to-one interviews she conducts with 10 informants, aged between 25 and 54. All of them have jobs (in or around Sydney), ranging from senior executive to junior assistant positions, and all of them are suffering from incurable illnesses that are not immediately or constantly visible. These conditions include MS, leukemia, glaucoma, spondylolisthesis, breast cancer, endometriosis, chronic fatigue syndrome (CFS, or myalgic encephalomyelitis, ME), lipodystrophy, and lung cancer. The complete list is longer because although some of the informants have the same illness (two have endometriosis, and two have MS), some have several simultaneously.

In addition to an analysis and discussion of the transcripts, there is an extensive literature review, and a detailed account of how the methods were chosen, the informants found and enlisted, and the work carried out. These elements provide a robust theoretical model within which the researcher's own experience and that of the informants, as well the ways in which they interact, are shown to be inseparable parts of the study as a whole. The material from the informants and the literature is supplemented with extracts from the author's diary.

The data converge on four main points: the trauma of discovering one has an incurable illness, and how this gradually turns "from crisis to chronicity"; the fringe-dweller status which chronic illness seems invariably to bring with it, whether in employment or out of it; worries about being able to do and keep one's job in a managerialist environment; and surviving.

The diagnosis marks an important point in the journey, but not the start of it, which occurs with the first awareness of the symptoms, in some cases a long time before the illness is officially labelled. Fred, after nine months of visits to doctors and specialists about a pain in his arm, is told one day in October that it's lung cancer and he probably "won't see Christmas". Daphne experiences loss of peripheral vision, aching, fatigue, ataxia and other gradually more persistent symptoms for seven years before being diagnosed with MS. Her response, paradoxically, was one of relief, at least initially: "It's good to know exactly what it is so you can deal with it," she says. Linda says "In May 1994 I was having a shower and I felt a lump under my nipple." She puts off going to the doctor, hoping it is a harmless cyst, but eventually she goes, is sent for a mammogram, then for a biopsy, and learns: "it was pretty serious ... so they couldn't actually just take a lumpectomy, they couldn't just take a lump out. They actually had to remove the whole breast." All this took a week.

Although it is hard to think of anything more daunting than one's own depletion and death, this discovery is only the beginning. The literature and experience alike indicate that "those who have the greatest need for social support are, frequently, the least likely to get it". Shelley, who has leukemia, remembers receiving loads of flowers and "cakes and all that kind of stuff" in hospital, but, returning to work, far from receiving emotional support, she actually loses friends because of inability or unwillingness to face another's suffering and death. Either she is assumed to be well because she looks well, and so her weaknesses are treated with indifference or impatience, or, to those who know that she is seriously ill, she is a source of discomfort and avoided.

Linda, returning to work after her mastectomy, is told by her manager: "Your job no longer exists."

"Do you realize that what I've got is a life-threatening disease?" she asks.

"Yes, but I didn't really factor that in when I was thinking of what to do with you," he says.

Much of the material focuses on this kind of exchange, which can be as devastating as the diagnosis itself, given its cruelty and its potentially disastrous financial and social implications. A stunning display of ignorance on the manager's part, we may say, but at the same time a perplexing one, because in these examples the manager functions in the way managerialism encourages us all to. Efficiency, the budget and the organization are what matter, it asserts. If human beings are acknowledged to matter too, it is because they are resources, the shrewdest investment, at least the healthy ones, or those whose diseases are curable. Not surprisingly, depression rates soar in societies where this understanding of life and work takes hold.

"Inhumanism" is not what successful mainstream workers and managers would usually claim to believe in, but it is perhaps the most accurate name for a set of values which systematically makes a virtue out of brutality and replaces human understanding with crude calculations (or, as is often the case, sophisticated ones). Productivity itself is revealed as a dubious rationale in this context. Surely work is valuable first and foremost as a means of living humanly.

Having braced ourselves for unmitigated gloom, however, and read about kinds of distress which are commonly considered unthinkable, we are left somehow convinced, perhaps more deeply than before, of the value of life. This is partly conveyed, though not explained, by diary extracts such as the following:

"As I write this, however, the first concentrated effort I have managed since entering the hospital five days ago, I can feel my toes, intermittently, for the first time in six months. I feel an *irrepressible* and ridiculous sense of optimism" (italics in the original). The hope nurtured here is not the false one that our illness and death can be ignored or postponed for ever; two of the informants die before the study is completed. It is that the blindness of instrumental thinking — which is the unseen chronic illness of the workplace itself — is perhaps not incurable after all. ■

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Urban health & development: a practical manual for use in developing countries

By Beverley Booth, Kirian Martin, & Ted Lankester
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This is a manual for development practitioners working with poor urban communities to improve local health conditions. It provides background information on the health problems typically encountered in such an environment, and outlines steps that can be taken to avoid or solve them.

Largely on practical grounds, the authors advocate treating communities as partners in (rather than recipients of) development. The book is written in simple and straightforward terms, with little concern for complexity, uncertainty and variability. The basic formula is one of working with community groups to: understand what the health-related problems are; decide what to do about them; and do it. Despite the emphasis on partnership, the basic institutional template is largely predetermined, and involves a 'Community Health and Development Programme', with a 'Programme Team' (made up of health specialists, development specialists and support staff), a Community Action Group (which can be based on a pre-existing community group), and jointly developed projects.

The range of health care and environmental initiatives described here goes well beyond the mandate of a typical government health authority. For the most part, it emphasizes preventing ill-health rather than treating it. Indeed, the authors suggest that it may be best to avoid using terms like 'community health committee', since the 'health' label may unnecessarily focus activities on medical care.

To some extent, this broad scope reflects one of the strengths of community health initiatives. In urban settings, health is usually worst in low-income areas, where health threats are closely linked to poverty, social exclusion, and unhealthy living and working environments. Working with poor urban communities, it is not only possible to target some of the most unhealthy groups, but also to focus on measures because of their importance to health, irrespective of whether the measures are a priority for local or national health

authorities, who must define their role in relation to other government agencies. If this means working to clear drains, set up day care centres or rebuild houses, rather than setting up health clinics, so be it.

The authors focus on initiatives that relate either to health care or to environmental health improvements, and require at least some degree of health expertise to handle. One could argue for a narrower focus, so as to stay within the bounds of available skills, or for a broader one so as to include important factors such as income-generating activities, but overall they present a coherent combination of health-related issues.

Another potential strength of community health initiatives is that they can adapt to local conditions, and do not have to prejudice how best to proceed, but it is just here that the book runs into more serious difficulties. Written from a 'How-to' perspective, it attempts to outline the practical steps required, not only to set up a partnership with the community, but also to tackle problems as diverse as tuberculosis and HIV/AIDS, domestic violence, and inadequate water and sanitation. The authors have clearly found it difficult to define steps that are sufficiently general to be widely applicable and sufficiently specific to be meaningful. This is hardly surprising, given the enormous diversity in low-income settlements around the world ('slums' in the book's terminology), and the complexity of the problems faced there. Unfortunately, as a result, strict adherence to the recommendations the book makes would undermine the flexibility of community-based health initiatives.

In attempting to provide a simple, straightforward presentation, the authors have also tended to rely on a representation of a typical 'slum' that comes close to being a stereotype. This effect is only slightly offset by boxes containing examples, sprinkled throughout the book. Stereotyping can easily prejudice development workers, especially when it extends to descriptions of the way 'slum dwellers' think and behave. Consider, for example, the problem presented first in the list of obstacles that can undermine efforts to develop partnerships with communities: **"Dependency mind set.** Politicians, government agencies and NGOs frequently offer to provide slum dwellers with certain services, or to enrol them in some scheme.

Over time, the people begin to feel it is the responsibility of these agencies to solve their problems. Therefore when a CHDP (Community Health and Development Programme) comes in and encourages the people to solve their own problems, they show no interest, resist, or may even be hostile."

This concern comes up a number of times in the book, and is undoubtedly based on the authors' considerable field experience. But describing a 'dependency mind set' in this way involves some sweeping generalizations that could easily reinforce prejudice rather than facilitate good relations, especially among those development workers already too inclined to blame problems on the way poor people think.

Somewhat analogous difficulties arise in relation to the health problems themselves. In their very brief account of indoor air pollution, for example, the authors write that "There are two dangerous forms of indoor air pollution in crowded slums". The first "comes from the use of open fires with polluting fuels such as kerosene, coal or animal dung..."; the second "is the effect of tobacco smoke..." Even if from an international perspective these were the two most dangerous forms of indoor air pollution in 'slums', they would be quite likely not to be the most dangerous in the community in question. Indeed, there are many areas where, from a health perspective, kerosene is likely to be a considerable improvement over wood.

In short, the very premise of this book — that it is possible to generalize about how best to pursue health improvement in low-income urban areas — is questionable. At least in its current edition, it would be a mistake to see this book as a recipe for developing community-level health initiatives.

On the other hand, the topic is of immense importance and the authors clearly have a great deal of experience. Most practitioners are likely to find the simple didactic style far easier to read than a more rigorous but complex and qualified presentation. Many will appreciate its urban focus, and its wide ranging content — which even extends to topics such as soliciting support from government agencies and fund-raising. It may not have achieved its over-ambitious goals, but it takes an important step in the right direction. ■

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