On the definition of relevant disease

Historically the art of medicine was defined by the ability to develop a personal reference for normality. This internal reference allowed the subjective identification of abnormality by pure clinical acumen. In contrast, modern medicine provides an objective scientific definition of abnormality, based on accurate measurement and statistical analysis. However, the medical profession still struggles to find the optimal balance between the art (subjective) and the science (objective), in providing holistic health care.

Statistical differentiation into normal and abnormal serves us well when dealing with continuous physiological variables like blood pressure, cholesterol, or weight. The differentiation becomes problematic when dealing with the complex biological balance that exists between infecting organisms and host responses. The initial simplistic differentiation into harmless colonising organisms and dangerous invasive pathogens has been replaced by a more complete appreciation of the complex, dynamic relation that exists between the host and the organism. The challenge facing modern medicine is to translate improved scientific understanding into clear, pragmatic guidelines applicable in diverse settings.

Once abnormality is identified, whether subjectively or objectively, the crucial question that remains is: Does this abnormality constitute disease? Disease is defined by present reduced quality of life (morbidity) as well as the increased risk for future morbidity or mortality. Knowledge of a condition’s natural history becomes invaluable when initial morbidity is minimal. Accurate description of the natural history of disease allows scientific risk:benefit analyses of a proposed intervention. The scientific identification of end points of the disease process is to quantify the relative benefit of the suggested intervention within a particular setting.

The idea of relative benefit or risk, to an individual within a particular setting, differs from the classical public health approach. With this approach the relevance of disease is determined by the total burden placed on a specific society, completely ignoring the individual patient. Although it insists with focusing scarce resources, it undermines the moral basis of the medical profession, which promises sympathetic care to every individual who seeks help. In contrast the concept of relative risk maintains the primary focus on the individual patient, but takes the baseline risk determined by his/her particular setting into account.

Relevant disease defines the point where relevant intervention crosses significantly beyond the baseline risk within a particular community. This implies that contrary to the classic public health approach, any severe disease represents relevant disease, irrespective of its contribution to the total burden of disease. This definition also challenges the classic pharmaceutical approach, which promotes any statistically significant benefit measured against a minimal baseline risk, as the accepted “standard of care”, irrespective of the particular setting.

Identifying the appropriate intervention once relevant disease is diagnosed requires careful analysis, weighing the relative risk posed to the individual and society against the possible benefit, risk and cost of available treatment. The challenge posed by the concept of relevant disease, is to identify the sub-population at highest risk in order to focus cost effective interventions appropriately.

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BOOK REVIEWS

They prayed for a miracle

The diagnosis of a cardiac problem which cannot be treated by conventional means must come as a devastating blow to the parents, family, and friends. Cardiac transplantation offers the prospect of survival in the medium term but there are significant problems. It must be difficult to take on board all the information with regard to the illness and potential treatments, particularly if the illness has been relatively acute. This book is a series of contributions from the patients and families on how they coped or had difficulty coping with this situation.

The book provides essays covering a wide spectrum from those where the outcome was seen as very good, full of hope and optimism to cases where the outcome was poor. The observations of the patients themselves, parents, grandparents, and cousins are all included and are eye opening reading.

There is little doubt that many families placed in this most traumatic situation would find this book useful. They will find details of patients with pictures and hand drawings made by patients highlighting the fact that these are all very real cases having come through major ordeals. The balance of cases which do not go well and have significant and severe complications is preserved with some extremely illuminating contributions from families where transplantation was not a successful strategy. There are also useful insights given by the patients themselves on what might be considered more minor complications such as frequent venepuncture and potential problems associated with immunosuppression.

The book was written and presented in a way that makes it easy to read and will be welcomed by many parents placed in this situation. Medical, nursing, and all the other staff dealing with the issue of transplantation would also find many of the observations made by the patients and families interesting and possibly change some of the ways information is relayed and issues explained.

I would happily recommend this book to the families of potential cardiopulmonary transplant recipients and to the professionals dealing with these patients and families on a regular basis.

J O’Sullivan

Protecting children from abuse and neglect in primary care

The world of child protection is constantly evolving, perhaps not so much as one might think. The report of the Victoria Climbié inquiry, chaired by Lord Laming, was published last year. As most will know, it details the catalogue of abuse and neglect which this young girl suffered. It also contains 108 recommendations for change. Although the focus of most of these are on social care, police, and paediatric care, there are some specific to the place of GPs and primary care teams, including recommendation 9: “The Department of Health should seek to ensure that all GPs receive training in the recognition of deliberate harm to children, and in the multi-disciplinary aspects of a child protection investigation, as part of their initial vocational training in general practice, and at regular intervals of no less than three years thereafter.”

A mismatch at the centre of child protection has long been recognised—that the primary care team (including GPs) are often in an excellent position to provide an informed assessment of a families’ abilities and struggles over time. Yet they often remain peripheral to child protection proceedings when they occur, whether through lack of time to attend meetings, or lack of experience in the field of child protection, or myriad other reasons. This book attempts to address part of that mismatch, by providing information about child protection targeted at primary care practitioners. In doing so, it may also fill part of the training gap identified by Lord Laming—even though it was produced before his report.

A lot is packed into the 256 pages of this book. It is edited by Michael Bannon and Yvonne Carter, a paediatrician and a GP, both with child protection experience. There are 24 other contributors, many of them authorities in their field. A large range of topics is covered, from information about the main types of child abuse and neglect, to less often covered (but important) topics such as domestic violence and adults abused as children. The style, and with it the utility, of the chapters varies. Some are clearly targeted at primary care professionals and written in an easy to read style. Others are more densely written and less orientated to general practitioners. For most primary care staff there is likely to be much of use within the book. For those more frequently involved in the child protection process, including paediatricians, there may be some useful reminders of things forgotten and some useful updates on key areas of child abuse and neglect.

P Ramchandani