Assessing psychosocial/quality of life outcomes in screening: how do we do it better?

We read with interest McCaffery and Barratt’s editorial on assessing psychosocial and quality of life outcomes in screening.1 We agree that it is necessary to show greater concern about the reliability and validity of outcome measures used but would also argue that it is equally as important to be clear about which outcomes are being assessed and how outcome data should be analysed and interpreted.

In their study Marteau and colleagues selected five items from a generic measure of health status (the SF-36).2 No explanation was given of why these particular items were selected, why they should be added together, what the label “self assessed health” actually means, or why it was relevant to the study. The five items clearly assess more than one construct. The item asking for a rating of health is a measure of impairment while the other four assess health beliefs that may have no relation to health status. Thus it could well be concluded that the study shows that the outcome measure used lacked construct validity. Health beliefs may well change in the presence of ill health but it would be expected that such changes would occur over a prolonged period of time. No assessment of quality of life or true health status (often referred to as health related quality of life) was made in the study. In this respect the outcome measure used lacked construct validity.

When adding scores of items together an assumption of unidimensionality is made. There is no justification for adding together scores of items that measure different constructs. A major problem with the scaling of the SF-36 scales presented in the manual is that it relies on correlations. However, dimensionality, additivity, and item ordering should be established using item response theory (IRT) evidence shows that the SF-36 scales are not unidimensional and that items in the subscales cannot validly be summed in this way.3

The outcome measure used by Marteau and colleagues failed to detect any impact of the screening process. This could have been predicted given the selection of items that are not clearly related to the screening process. It is clear that where there is an interest in the process of screening itself it is essential to use outcome measures that are specific to that situation. As mentioned in the editorial only a few measures specifically developed to measure the consequences of screening are available. However, for example, the psychological consequences questionnaire4 lacks content validity when measuring consequences of false positive screening mammography.5 Further research is needed not only to develop instruments that capture the psychosocial consequences of screening adequately but also to ensure that these instruments meet the modern psychometric criteria.

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Authors’ reply

In our recent paper in the journal we present data showing that self assessed health predicts the presence of an abdominal aortic aneurysm independently of known risk factors. In an accompanying editorial, McCaffery and Barratt note this interesting finding and reinforce our conclusion regarding the importance of including measures of psychological outcomes at baseline to avoid erroneous inferences regarding the psychological consequences of screening.6 Brodersen et al.6 criticise our choice of outcome measure, namely self assessed health, on two counts. The first concerns the psychometric properties of the scale selected; the second concerns the validity of assessing generic as compared with context specific outcomes.

We measured self assessed health using the five item scale: general health, taken from the SF-36 for which there is good evidence of internal reliability.7 Validating a measure of self assessed health is more difficult. A measure of “true health status” as suggested by these correspondents would not suffice. Indeed, the literature on self assessed health is of enduring fascination precisely because self assessed health is not synonymous with “true health status”.

Regarding the use of generic as compared with screening-specific outcome measures Brodersen et al. take a firm view arguing that “it is essential to use outcome measures that are specific to that situation.” There is good evidence that participation in screening programmes has psychological consequences that are deteretable using both generic and specific measures.8 The choice of outcome measure should of course depend critically upon the research question. If one wants to know for example whether screening for risk of heart disease causes depression then a generic measure of depression is needed. By contrast if one wants to know whether screening for risk of heart disease causes increased worry about heart disease, a more specific measure is needed.

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BOOK REVIEWS

Statistics for epidemiology

A range of books, some excellent, have been published on the analysis of epidemiological data. While some focus mainly on the underlying epidemiological concepts glossing out the details of the underlying statistical methodology others provide an advanced course on statistics requiring a strong grounding in statistics from the reader. Statistics in Epidemiology has just the right balance between these two approaches.

The book has been developed from a graduate course in statistical methods for epidemiology taught in the School of Public Health at Berkeley, focusing mainly on the analysis of epidemiological studies with binary outcome. It progresses logically from elementary analysis to more complex logistic regression models. Alternatives and extensions to logistic regression models are briefly outlined at the end. Using the same examples throughout the book, the author helps the reader to compare and contrast the different approaches and to appreciate their similarities and the limitations. The excellent introduction to the concepts of causal graphs and their use in understanding and controlling for confounding is a great strength of the book. At the end of each chapter the author provides comments and further reading, pointing to relevant statistical textbooks and articles. The carefully selected problems and exercises (solutions to which are provided at http://www.ctexp.com/e_products/downloads) help the reader to gain an in-depth understanding.

Overall, the book is well written, comprehensive, and well structured. The author, through step by step development of the concepts, successfully shown the hazards of going straight to a complicated analysis, before gaining a proper appreciation of the underlying epidemiological concepts glossing the data. I personally found it very pedagogical and instructive. I therefore strongly recommend it to all graduate students and researchers in epidemiology or relevant fields. The book is a good reference for teachers giving similar courses.

Giota Touloumi

Vaccines. Preventing disease and protecting health

This is an excellent update for professionals working in immunisation programmes. It is presented in a very pleasant, easy to use edition and includes the papers presented at the symposium “Vaccines. Prevention and public health: a vision for the future” organised by the Pan American Health Organisation in November 2002. The book’s chapters are written by leaders in their fields and discuss the progress achieved by the use of vaccines in most of the world’s immunisation programmes. It also describes the state of introduction of the newest vaccines currently available for immunisation and reviews progress in the development of vaccines against HIV, malaria, dengue, and other bacterial and viral diseases responsible for much mortality attributable to diarrhoeal and acute respiratory illness. In addition to an epilogue that deals with the programme and conclusions of the conference, the book contains a setting the stage section that tackles emerging and re-emerging diseases and immunisations in the past century and eight parts containing 44 short chapters that are easy to find and to read.

Parts I and II review vaccines against diseases for which there are current immunisation programmes of elimination (polio, measles) or control (rubella and others), with the chapter “Accelerate control of rubella and prevention of congenital rubella syndrome” by Gina Tambini et al, being of special interest. Parts III and IV deal with vaccines that are not yet included in immunisation programmes. Part V includes a set of novel, interesting chapters on adjuvants and delivery systems, DNA vaccines, oral vaccines from transgenic plants, and epidermal delivery of DNA vaccines). Part VI contains six chapters about vaccines that actively considered the most useful in preventing possible bioterrorism attacks, such as smallpox, anthrax, and viral haemorrhagic fevers. Part VII and VIII dealing with regulatory and safety issues and the role of vaccines in prevention from the public and health perspective. The chapters entitled “The consumers’ perspective”, by David Salisbury and “Perspectives for the elimination/eradication of diseases with vaccines”, by Walter R Dowdle are especially interesting. The only weakness of the book, any, is the bibliography: although one chapter includes up to 83 references, eight chapters have only three or less.

In summary, this is an important book that I strongly recommend to those working in public health and vaccinology.

Angelo Dominguez

Learning from HIV and AIDS

The chapters in Learning from HIV and AIDS come from talks presented at a multidisciplinary symposium organised by the UK BioSocial Society in May 2001. The goal was to transcend the more traditional question of what we have learnt about AIDS, and instead to focus on what we have learnt from AIDS.

The organisers hoped to provide a framework that would foster inter-disciplinary and intra-disciplinary collaboration that would improve our ability to deal with the biological, social, and political challenges brought about by the epidemic. It was hoped that the symposium would shed light on advances in a variety of scientific and psychosocial disciplines that have been brought about as a result of the AIDS pandemic, leading to a more holistic, multidisciplinary approach to our understanding of this disease, its consequences, and our attempts to control it. Disciplines represented in this book include infectious disease, clinical medicine, epidemiology, demography, behaviour change and prevention, anthropology, political science, and even history.

The contributors of this book have succeeded in their assignment to varying degrees. Like most multi-authored books compiled from symposium presentations, this is an uneven collection. Some of the authors did their homework as assigned: the chapters on epidemiology and demography, for example, explicitly detail the disciplines resulting from study of the AIDS pandemic. Others, such as the comprehensive chapter on HIV and the evolution of infectious diseases, focus more on what we have learnt about AIDS itself. Some authors use their chapters to discuss weaknesses in the current state of research. For example, the chapter on behaviour change focuses specifically on the research on the effects of behaviour change and disease prevention as a result of the AIDS pandemic would have been of greater interest to the general reader.

Catherine Pritchard

Building better health. A handbook of behavioural change

An understanding of health promotion is an essential foundation for all health professionals. Building better health focuses on the themes of disease/illness prevention via health promotion and integrates theory with practice. The book is divided into five parts; laying the foundation, improving health throughout the lifecycle, better understanding the leading forms of death and disability, intervening more effectively, and the epilogue. The initial chapters concentrate on the imperative for health promotion setting out the economic and moral standpoint. In particular emphasis is placed on the importance of engaging the community in improving health. The multiplicities of factors that impact on health are discussed. From this point the book examines health issues across the lifecycle from pre-natal care to old age. Throughout these sections practical examples are provided that could be applied in many settings. Chapters related to effective interventions provide a useful background to the theory of behaviour change. The array of references could be further used to explore this complex area. The importance of working with communities to achieve change is a central tenant of the book with the proposal that “convenience, convenience, convenience” should be the mantra to aid community participation. The final part of the book provides an interesting look at the dilemma of prevention compared with treatment.

The book will appeal to a wide audience with an interest in health and health promotion. The format enables the reader to focus on a particular section if so desired, but is also sufficiently user friendly to enable it to be read from cover to cover. The book is global in appeal as the examples used are from across the world in preference to many that concentrate solely on health impacts in the western world.

Catherine Pritchard
Two chapters, while fascinating, seemed somewhat out of place. One provided an intriguing look into HIV transmission among gay and bisexual men in the backrooms of London from a descriptive anthropological perspective, focusing less on research and more on advocacy of a different approach to prevention. In a book that deals mostly with research issues and that focuses primarily on HIV/AIDS in Africa, this chapter felt a bit lonely. The nod to the clinical sciences was a thoughtful and personal account by a physician in the UK, in which he discussed his experiences treating HIV infected gay men and immigrants in London, including his battles against the many obstacles to their care. I should disclose the fact that I’m a clinician and a clinical researcher—perhaps not the most appropriate reviewer for a book dealing primarily with non-clinical disciplines in the study of AIDS in developing countries. But a chapter on what we have learnt in the clinical sciences as a result of AIDS would have been an easy one to write, and its absence in a book that otherwise attempts to span the breadth of the disease from micro to macro was glaring. Also missing was an in-depth discussion of the role of patient advocacy and activism in the AIDS epidemic. While it is mentioned in passing by several authors, it deserves a chapter of its own, as it has dramatically changed the way patients view their own health and illness in the developed world, and is now beginning to become a factor in developing countries as well.

While Learning from HIV and AIDS sometimes misses its target, I found the individual chapters fascinating, approaching them, as I did, as a clinician and therefore an “outsider.” This book would be valuable for anyone working in the field, especially in developing countries, whether as a researcher, policy maker, or field worker. It succeeds in reminding us that there are many ways of looking at an epidemic, ranging from the focus on the microbiology of the infecting organism, to the epidemiology of the spread of that organism within communities and societies, to the behavioural and anthropological factors that facilitate transmission, and finally to the socioeconomic and political factors that can either slow the epidemic or impede our efforts to control it. While it is tempting to focus on the discipline we know best and (as some of the contributors do) to minimise the importance of the other disciplines, Learning from HIV and AIDS reminds us of the importance of the bigger picture—to know how those in other fields think and what they have learnt. Just as physicians are taught to take a holistic view of their patients, it is important that we also view epidemics holistically. It is unlikely that the global AIDS pandemic will be brought under control by any one discipline in isolation.

Joel E Gallant

Accessing health care: responding to diversity


The focus of this book is on the level of inequalities in access to health care services faced by diverse populations with a high level of need, which may be exacerbated by unprotected systems of human rights, and the inability of health care services to respond to specific needs. Different chapters present case studies of unequal access for three broad categories of vulnerable populations linked to socioeconomic status, weakly defined citizenship, and polyethnic societies (including studies on prison, asylum seekers, and Roma populations). The book takes an original approach, being the first to attempt to collect varied information to describe and/or evaluate experiences targeting these population groups. This topic is highly relevant in the current context of growing diversity and movements of populations between countries. The authors show that strategies to tackle the defined inequalities should depend on context, entail cooperation with other areas of social policy, and should consider cooperation and attitudes. The choice of a delivery model should therefore be context and group specific, and take into account possible trade-offs with other objectives that policy makers may wish to achieve. Innovative and responsive programmes for the special needs of special populations are required, which however, also creates difficulties in evaluating these programmes. The volume could have been improved with a more systematic treatment of barriers to access across chapters and by making more explicit links between unequal access and current trends and issues in health care reform (that is, equity compared with cost containment or devolution). The concluding section might have been strengthened if it had adopted a similar structure to earlier parts the book, as the population groups seem to have common access issues. Reducing some sections in the book, for instance those covering historical background, might also have been beneficial. Given that most of the problems outlined in this study apply to low income countries, some reflection on this fact and the particular challenges faced in these settings would be of great value. The book is accessible for a non-technical reader and is an important contribution as an introductory text in this area.

Mónica Oliveira