Topical Reviews in

Rheumatic Disorders

Volume One

Edited by A. G. S. Hill

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EDITED BY

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Bristol
John Wright & Sons Ltd
1980

Published by John Wright & Sons Ltd., 42–44 Triangle West, Bristol BS8 1EX.

British Library Cataloguing in Publication Data

Topical reviews in rheumatic disorders.
Vol. 1.
1. Rheumatism
I. Hill, Alan George Seymour
616.7'2 RC927

ISBN 0 7236 0554 8

Printed in Great Britain by John Wright & Sons Ltd.,
at The Stonebridge Press, Bristol BS4 5NU

Preface

A volume of this nature, unlike a textbook, does not commit its editor to a comprehensive survey. Free from such constraint he can aspire not just to instruct but to convey some of the excitement of the current scene. I hope this volume will appeal not only to those active in clinical rheumatology and related laboratory research, but to enquiring readers whose interest can be readily kindled by intriguing advances in any branch of medical science. To this end a collection of essays rather than detailed theses seemed appropriate. It was not so much a matter of choosing topics and then seeking people to write about them, as of assembling a team whom I knew to have devoted years of fruitful work and constructive thought to problems which had fired their enthusiasm and which appealed to me. Some were invited to choose their own topic, all were urged to give an account which was very personal. They were not necessarily obliged to explore in detail the work of others. The idea was to capture the spirit of good scientific meetings during the discussion of a formal presentation. The presenter of the paper is conventionally constrained from speculating much beyond the bounds set by his own data. In discussion an audience is ready to accept opinions from those whose authority they respect and does not demand a detailed exposition of the knowledge and thought on which they are founded. Individual authors interpreted these elastic terms of reference in a variety of ways. No uniform approach was sought or desired but speculation about future developments was encouraged.

For the first chapter Dr Philip Wood and his colleagues chose an enigmatically enticing title and readers attracted thereby will be rewarded by a lucid and coolly critical appraisal of medicine in the setting of a changing social structure. Most of their observations are pertinent to the whole medical scene and to the varied provisions for care and welfare evolved by industrialized nations, the National Health Service of the UK being but one model. The expectations of patients with rheumatic disorders and the extent to which they are fulfilled are set within the broader scene, but there are important, perhaps disturbing, messages for all. Within this wide setting the fundamental unit of medical care is still to be found where patient, doctor and disease converge and it is at this point that accurate diagnosis satisfies alike the intellectual aspirations of clinicians and the needs of patients for treatment which is soundly conceived. The chapter by Professor Ralph Jacox contains fine examples of the art of medicine practised by a master in diagnosis; it leaves us in no doubt that clinical science holds its own with the laboratory. The contributions of orthopaedic surgery to the management of arthritis are undisputed. But those a little removed from the integrated medical–surgical expertise of rheumatology units may find some difficulty in distinguishing operations which can be recommended with confidence, given that the correct indications are present, from those which are controversial or still in the stage of development or refinement. In my own chapter I have tried to resolve this difficulty, concentrating on indications for invoking surgical

help rather than technique. But future progress is largely directed by advances in technique and nowhere is this more evident than in the prosthetic replacement of damaged joints. In a chapter which is a product of the fruitful alliance of medical science and engineering Professor Verna Wright and Dr B. B. Seedhom offer a critical review of the present scene. We are reminded that success, still not entirely unqualified, in replacing the hip derives as much from the favourable geometry of this joint as from the nature of the prosthetic materials now most commonly used. But we see that advances in the technology of plastics and metal have failed as yet to solve all the problems of the knee with its more complex geometry. And we are brought back to the stark reality of the constraints, already touched upon in the first chapter, which enforce delay in bringing to patients the prompt relief of pain which replacement of the hip can offer. Like Dr Wood and his colleagues, the authors see the possibility of preventing or curbing damage to joints in rheumatoid arthritis by the use of slow-acting drugs such as gold or penicillamine. There is no more than a ray of hope here, but continued and perhaps increasing interest in 'antirheumatoid' drugs prompted the inclusion of a chapter by Dr Hilary Hill on the subject of penicillamine. This fascinating drug, so varied in its actual and potential actions, undoubtedly influences many manifestations of rheumatoid arthritis in a favourable way. The final place of penicillamine will be determined by success or failure in reconciling efficacy with an acceptable risk of injurious effects. As yet there is no certainty that an ideal balance can be struck, but with the help of new data about medium and low doses the author has narrowed the range of dosage within which it should be sought. She highlights the vital importance of meticulous monitoring during treatment whatever dose is used. Finally there are two chapters about genetic and environmental factors in pathogenesis. Studies of HLA antigens have brought a new dimension and enhanced precision to understanding of the genetics of disease, not least of conditions which are within the sphere of rheumatology. Dr Andrei Calin has provided a comprehensive survey of his own major contributions and those of others. In the last chapter Dr Michael Denman complements this review of the genetic background with a survey of the evidence pointing to a viral antigen as the environmental factor in the pathogenesis of rheumatoid arthritis. The case is hard to prove but the role of viruses will surely continue to engage the talents of investigators as an enticing trail to follow.

My task as editor has been a happy one. This book is the product of the knowledge and enthusiasm of a group of friends to whom I presented a concept which was clear in my mind but hard to define. They responded splendidly. It is much easier to write within narrower bounds but they let their thoughts fly freely and I hope readers will enjoy the fruits of their effort as much as I have done. I am grateful to them for their ready response and for their tolerance of my importunities during the gestation

period of the book. My thanks are also extended to Mr Roy Baker of John Wright & Sons for unfailing help and encouragement, to my secretary, Mrs Lesley Watts, and to Mrs Diana Gulland of the Wilfred Stokes Library at Stoke Mandeville Hospital who gave invaluable help with references.

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1 Other Waters Flow

An examination of the contemporary approach to care for rheumatic patients

Our title is derived from a fragment by Heraclitus dealing with flux: how you cannot step twice into the same river. The world of today is not that universe into which, like larvae, we emerged newly qualified. It therefore behoves us to question to what extent we have kept abreast of change. Although concerned primarily with rheumatic diseases, we have had to take account of much more general changes that also influence practice.

Therapeutic advances have generally been welcome, and to these we are likely to have responded with avidity. Not so to mutations in the health care system; these are more threatening. Some have been institutional, such as the introduction of Medicare and Medicaid in the United States or the reorganization of the National Health Service in Great Britain. Others have been procedural, like the menace to the millimetre of mercury created by the advent of SI units. With both types of organizational change our feelings have usually been mixed; the system tends to compel adaptation, which itself kindles reluctance and a nostalgia for former freedom.

Society has changed in many other ways. The community now aspires to different values, ones that are at once more egalitarian and more demanding. A corollary has been challenge to the role and status of physicians. As a result we have come to resemble Matthew Arnold's Scholar-Gypsy:

> 'For what wears out the life of mortal men?
> 'Tis that from change to change their being rolls;
> 'Tis that repeated shocks, again, again,
> Exhaust the energy of strongest souls
> And numb the elastic powers.'

But in this depleted state we become less sensitive to yet other alterations that overtake us. It is a sad paradox that aspects of our patients may tend to be less compelling of our attention, so that we may fail fully to assimilate changes in them.

Our aim is to try to bring into focus these four strands, the community, the health care system, the physician and the patient, and then to explore the implications for health-related policies and, within that context, those of particular relevance to people suffering from rheumatic diseases.

THE COMMUNITY

As far as health matters are concerned, the most important changes in society relate to alterations in the burden of illness and in how such experiences are regarded.

Realization of Health Potential

The late 1940s was a period of optimism and even euphoria, with understandable aspirations to create a better world. New technologies exploited during the war were being freed from the demands of destruction, and therefore could now be applied to rebuilding and growth. Medicine was poised to play its part – not only were medical resources liberated from coping with mutilation and large-scale catastrophe, but the development of antibacterial drugs had provided weapons with which to attack the principal killer diseases, the infections.

The other major determinants of ill health and disability, poverty and deprivation, had also come to be regarded differently. The long years of economic depression had taught that people like the Okies or the inhabitants of Jarrow could not individually be held responsible for their destitution. Thus Samuel Smiles and his nineteenth century views lauding self-sufficiency were revealed as offering altogether too simplistic a neglect of complexity and interdependence in our society. The interdependence was reinforced during the ensuing conflict, when the socially disadvantaged were seen to make the same sacrifice as anyone else; one of the first American casualties in the war was a Pima Indian, a fact represented on the monument commemorating the battle of Iwo Jima.

Health thus came to be regarded not just as good fortune but as a universal human right, a principle that was enshrined in the charter of the World Health Organization when it was established in 1948. The means to better health now existed, and all that appeared to be necessary was to devise ways of making the fruits of these advances available to all those in need. Unfortunately, the principal barriers were economic, at once placing the challenge at the heart of political values in society. Scruples about self-sufficiency and independence were outweighed by the community's debt to erstwhile belligerents so that special arrangements were made for repatriated veterans, privileges which in some circumstances were extended to their families. The greed for labour during postwar expansion also helped to erode ideological obstacles, and this period saw the development of occupational health insurance, industrial medical schemes, pioneer rehabilitation services, and a variety of welfare provisions, each of which contributed to broadening the availability of medical care.

Disease Burden

The introduction of a national health service (NHS) in Great Britain during this period is of more than parochial concern. Most industrialized countries developed some form of improved health or more enlightened welfare

provision in the years immediately following the war. Disregarding ideological issues, the interest of the NHS is that its supposedly comprehensive coverage and support by diverse welfare measures provides a model for assessment of the impact of sustained confrontation on the determinants of ill health.

The architect of Britain's welfare state, William Beveridge, had imagined that, once the backlog of neglect had been dealt with, demand for health care would diminish – as if there was a finite quantity of ill health that needed only to be overcome. This belief in what we would now regard as the cost-effectiveness of health services appeared to justify the investment, because the commitment of resources should have been self-limiting. It was as if the enlightened harnessing of science and technology for the benefit of the whole community was expected to lead to the millennium, universal health, once poverty and deprivation had been banished.

Such optimism was not entirely lacking in validity, and in many ways the success of universal health care has been responsible for transforming the situation. In reality what has happened is that the solution of one set of problems has served only to reveal fresh ones, as other waters have continually flowed in, and inevitably the difficulties that remain are more intractable. Thus although a large part of acute and life-threatening illness has been conquered, an alarming burden of chronic disease has emerged to take its place. Far from demand diminishing, the very nature of rheumatic and other chronic conditions gives rise to repeated and continuing calls on health and welfare services.

There have been a number of other important changes in the community. Alterations in the nature of the disease burden have been compounded by changes in demographic structure. Reduction in childhood mortality in the early years of the present century has resulted in a proportionately larger cohort that, over the last thirty years, has approached the end of its biblical span. Thus the size of the population at risk to the altered disease burden has increased, contributing further to the dominance of chronic illness. Furthermore, the relationship between productive and non-productive segments in the community has changed in consequence, with economic implications that are obvious.

Expectations

In fact, we have witnessed a duality of change. Not only have calls on services not fallen off, they have in fact been magnified by increased consumer expectations of the services. Three important factors have each played their part. First, removal of economic barriers, developments in technology, and a sense of what is fair have encouraged the view that, to borrow from *As You Like It*, 'the last scene of all' should not be 'mere oblivion'. At least the national health could prevent the seventh age being sans teeth and sans eyes, even if the flavour of life was still disturbed by

limitations in the provision of hearing aids and inability to overcome various other impairments.

Second, changes in occupational opportunity have promoted geographical mobility and family dispersion. As a result, the infinity of the extended family has been curtailed and this, together with urban renewal and rehousing, has tended to reduce an individual's social network, particularly if he or she is elderly. Personal resources for coping with dependence and adversity have generally diminished in consequence. To compensate for this there has been clamour for statutory obligation to meet needs that formerly were assimilated within the family. It may be tempting to bemoan the decay in duties and responsibilities between family members, but the record should be kept straight. Most often the problem is not absence but breakdown of family support, a situation compounded by geographical mobility and the fact that quantitatively the problem is much larger than of yore, not least because of the demographic changes already noted.

Third, expectations generally have increased. This century has been characterized by developing pressures for an egalitarian society, and world events have accelerated the trend. Thus conflict on a global scale, transformation of national economies to war effort, and universal mobilization of combatants have each contributed to erosion of status differentials. For instance, debacles of leadership in the first World War laid the foundations for the democratic illusion in the second that anyone was eligible for consideration for promotion to officer rank. Universal suffrage and improved education have at once acknowledged and promoted these developments, and in turn economic logic with the growing demand for an ever-wider consumer base has further reinforced them.

The health expressions of these more general changes have been quite marked. Expectations of health have led to reduced tolerance for even trivial symptoms, and belief in the potency and specificity of science has fostered the notion that medicine can control all such phenomena; although self-treatment continues to be important, calls on health services have increased inevitably. The change from charitable to insurance or state funding has altered the individual patient's status, so that physicians are now called upon to negotiate rather than command. Relationships that have not assimilated these developments lead to failures in so-called compliance, when looked at from the physician's point of view, and to considerable dissatisfaction on the patient's part (*see*, for instance, the work of Cartwright, 1967 [1]).

Disablement

So far we have been speaking very generally. This has been deliberate, to establish a foundation to which we shall refer back later. Moreover, the situation in relation to rheumatic diseases tends to be only a specific example of more general experience. This is true even when we consider the consequences of disease, particularly in terms of disablement; rheumatic

disorders account for at least a third of all significant physical impairments encountered in the community at large. Two aspects of disablement are pertinent to this part of our thesis.

The disabled individual experiences disadvantage when there is a clash between performance and expectations. As the range of life experience expands and is extended to larger parts of the population, so aspirations grow apace and the potential for disadvantage increases as a result. On the other hand, and despite technological progress such as with the development of improved materials for prosthetics and orthotics, the role possibilities for the disabled in society as it is are in fact tending to contract rather than expand [2]. We shall return to the implications of this observation later on.

Secondly, the world we inhabit is like Topsy, it has just growed. There have been a few purposive endeavours to improve the texture of life, such as by better housing, and it is important to recognize that the goal for these efforts has mainly been to relieve social deprivation. However, this has been conceived of within a population homogeneous for most attributes apart from class, wealth and opportunity. Migration and other changes that have occurred during our lifetimes have altered the nature of deprivation. A plurality of interests has emerged, so that increasingly the disadvantaged are identifiable as particular minority groups. Among these is one that already accounts for at least 2 per cent of the population, and is drawn from all walks of life. This is made up of the disabled, whose numbers can only grow as more and more of our people live out their full span.

THE SYSTEM

The health care system – the way in which health services are organized – has had a great deal in common in industrialized countries on either side of the Atlantic, despite individual differences. In all countries the system has been confronted by increasing complexity of hospital functions, rising costs of hospital care, and growing dependence on third-party payment or public financing.

Military and Industrial Models

Wartime experience had accustomed people to the concept of a task force. In the years that followed it seemed natural to exploit this notion as attempts were made to improve health service planning, regarding the hospital as the centre-piece of health care delivery. From what has been said about changes in the disease burden, this can now be seen as a response to the challenge that was tactical rather than strategic. The approach brought with it two other characteristics of a tactical response: short-term perspectives in management that were insensitive to alterations in health experience, and rather narrow preoccupations with efficiency that have not fostered the development of measures suitable for evaluation. Further-

more, this approach tended to promote concern with institutions, often to the neglect of functional services directed to meeting identifiable classes of need.

That the concepts and methods developed in military, industrial or commercial contexts might be inappropriate to health services management should be evident from consideration of the fundamentally different nature of these services. Perhaps most important, the objectives of health services tend to be intangible; they are usually open-ended and are rarely explicit, which means they are also difficult to quantify. Health services are labour-intensive, Britain's NHS being the largest single employer in the country. They are also expertise- or talent-intensive, an aspect which is usually associated with varying degrees of autonomy asserted by the different groups of health workers. On a different plane, the clients of the service tend to be cast in a rather passive role.

The contrasts with a closed and often authoritarian capital-intensive system are self-evident. Yet even as recently as 1974, when the NHS was reorganized, the differences had not been fully appreciated. Thus contemporary commercial management philosophies, including such components as consensus decision making, were inflicted on to a rigidly hierarchical structure. The functional goal was acknowledged as being maximum delegation downwards and accountability upwards. Not only may the consensus evade delegation and accountability, but the proposition is also problematic when it is recalled that much of what does and should happen is in the reverse direction; patients delegate much of their autonomy to the service (i.e. upwards) and, by Hippocratic tradition, it is to the patient that the service should be accountable (i.e. downwards).

The Challenge to Modern Medicine

By the early '60s greater awareness and concern for the elderly and the physically and mentally disabled had developed. This led to a variety of piecemeal initiatives both in Europe and North America, though these were still much influenced by an institution-centred philosophy that sought to expand the role of district hospitals. However, the relevance of such models was also beginning to come under scrutiny.

The key force for change was probably a growing realization that explosion in health care costs had not been accompanied by commensurate benefits in terms of increased life expectancy or reduced morbidity. Controversy over the effectiveness and value of medical care [3, 4] was augmented by re-examination of the nature of illness experience, both in evolutionary [5] and behavioural dimensions [6]. The very profound challenge that emerged was directed at both the level of understanding of sickness phenomena (i.e. the target of health service activity) and the consequentially questionable appropriateness of the system of care. Unfortunately, more extreme statements of denial [7] and itinerant

nihilism [8] perhaps served more to foment blanket rejection of the challenge than to promote serious examination of the issues raised.

In the background were other concerns. Equity was offended by persistent maldistribution of resources, Hart's Inverse Care Law [9] being exemplified by the variable availability of rheumatological services in most countries. In Britain we have looked on somewhat wryly at the way in which the Elephant (a district in London wherein are situated the principal offices of the Ministry of Health) has appeared to spawn white elephants – the monstrous new air-conditioned hospital complexes or health palaces, conceived mainly in the '60s before the energy crisis made them un-ecological and uneconomic to run, and so large as to encourage labour unrest through depersonalization and the remoteness of the individual worker from the essential service function for which these institutions were created.

Resources for Health Care

More and more it is coming to be recognized that hospitals fail to provide a cost-effective solution to a very considerable part of the problems that make up their current workload. In seeking alternatives, much attention has been paid to the scope of ambulant care at the primary level, and also to the degree of personal responsibility of those who become patients. The latter has led to increasing emphasis on prevention and on self-care and self-reliance. Blueprints for comprehensively integrated health care systems that assimilate these insights have become the vogue. In principle the ideas are attractive, but they call for far-reaching changes and their implementation is dependent on a wide range of resources. The issues can be illustrated graphically with infant mortality. Despite investment of considerable resources and effort, in both the United States and Great Britain this very sensitive indicator has failed to improve as much as in some other European countries. The potential limitations of the new emphasis are also apparent. Thus medical aspects of infant mortality, such as low birth weight, appear to be determined mainly by social factors like poverty. Any strategy that fails to deal with these non-medical determinants is obviously doomed to fairly circumscribed achievements.

Although there are essential technical aspects to health care, at root we are presented with human problems and it is human beings that have to identify and respond to these. Resources of personpower are thus critical. During most of the last thirty years we have lived through a period of expansion. This has accustomed us to seeing the recruitment of more staff as the remedy for so many problems. Some sectors are certainly still crippled by understaffing, but there are reasons for questioning this response as a panacea that are far more profound than resource constraints. Were the overall pattern of personpower expansion of the '60s and early '70s to be continued indefinitely, we should reach a situation at the beginning of the next century where half the population of the country

would be looking after the other half *in a professionalized capacity* [10]. Far from being a brave new world this would surely be akin to hell on earth, even if wealth allowed it to happen.

From inflation in staff we must now turn to economic crisis and the prevailing tendency towards zero growth. Models of constraint, as opposed to growth, and concern about a possible health personpower glut are beginning to dominate people's thinking, so that health is being sought at what is thought of as a reasonable cost – in other words, ideas of what is reasonable are changing. Hopes are vested in improved health service planning and the manipulation of resource allocations as the means of realizing this aim. Both inevitably lead to conflict with traditions of excellence in medicine, traditions epitomized by the tactic of leaving nothing undone on the margin of the impossible, as well as posing a degree of threat to the privileged status of physicians.

Relatively sudden alterations in priorities, between poorer as opposed to better endowed regions of a country or sectors of care (e.g. primary care and services for the chronically ill, in contrast to hospital-based and acute services) cannot help but be painful for those affected by curtailment. However, the major fault lies less with the constraints themselves than with the fact that the nettle of inequity was not grasped earlier. For instance, reluctance to interfere with local autonomy allowed too many hospitals to develop for too long towards the same level of specialization; witness dialysis facilities in many American centres, the excess provision owing more to status-seeking by each institution than to reasoned appraisal of population needs.

Resources are intimately interrelated with demand and with standards. Expectations about care for rheumatic disorders often contrast with those for health care in general by being unreasonably low [11]. As a result, demands for improvement have frequently not been expressed. Formulated standards have largely been lacking so that at best services have been uneven, and adequate care gets denied to considerable parts of the population. It is therefore hardly surprising that resources commensurate with the problems have not been applied to their solution in the past. A critical review of sector allocations in relation to population needs is thus likely to benefit rather than limit rheumatological services.

The means to augmentation of rheumatological resources are likely to come from the planning process. This compels one to consider how sensitive and how effective this is likely to be. The best known failing in NHS planning has been the lack of reliable information, even though on most planes Britain is better served than other industrialized countries with routine statistical data. Wrong assumptions about the real world by policy makers have also served to bring the exercise into disrepute. For instance, there has often been insensitivity to regional and neighbourhood differences, and yet local profiles of need and the outlook and receptivity of local decision makers and implementors vary quite considerably.

The most difficult aspect is flexibility in long-term strategic planning. The advent of total joint replacement surgery provides a good example. Here again the contrast with industrial enterprises is striking. On learning of triple injection fuel systems in automobiles the consumer may be interested, but waiting some years for their commercial availability is no undue hardship. On the other hand, and understandably, when it is his hip that is painful he wants instant gratification of the desire to benefit from whatever is surgically feasible. Despite the crisis, finance could be made available rapidly, and even the use of hospital buildings could be changed fairly quickly. However, the obsolescence rate in health activities is much less than in commerce so that these alterations are likely to be accomplished only at the expense of some other service. The critical constraint in a situation like this is people – orthopaedic surgeons, anaesthetists, nurses, and other operating theatre staff. Each takes a long time to train, and in this respect medicine is effectively a monopoly enterprise – there is no alternative pool of labour from which the staff can be drawn.

Decision Making

These various issues represent imperatives of choice and priority so that decisions have to be taken. Equally unsettling has been change in how and where the choices are made. Administrative realignment has not been confined to Britain. Plans for integrated health care usually incorporate a pyramidal structure, where the degree of specialization is related to a territorial base. This has led to changing attitudes towards community hospitals, as well as threatening the autonomy and degree of comprehensiveness of larger district hospitals. At the same time there has been a tendency to seek coterminosity with other local and regional authorities, and the latter have themselves often been reorganized and strengthened. This reorganization has inevitably altered the administrative structures to which we have to relate.

Over the same period political power has been relocated in a striking and yet contrasting manner in many European countries. On the one hand, there has been devolution to subnational levels, with more decisions being taken locally or regionally. On the other, there has been supranational erosion of the power of the nation state, the move towards harmonization of medical directives between members of the European Economic Community being an example of the latter. Thus we are having to follow new pathways if we wish our advice and influence to be heeded.

Two other aspects of decision making have changed. First, although the judiciary has so far escaped, both the legislature and the executive have been subject to increasing intervention by a fourth power, the interest groups. The latter have been exerting a growing influence on such matters as policy formulation, priority determination and the allocation of resources. The danger is that decibels tend to retard development of a balanced and equitable global appraisal of problems [12]. However, we