

of the medical schools will be doing this in the next decade, unless there is support for it that is equivalent to the strong support that has been given for 15 years in building up the more academically-oriented research personnel.

Nobody has mentioned the fact that some of the best postgraduate education comes from full exploitation of the referred patient. When a consulting group makes full use of the opportunity that is presented by a referred patient, they are helping the physician give excellent care to the patient that he has referred for consultation, and this is a most effective means of educating physicians.

DR. AMOS JOHNSON: Dr. Polley did a most excellent job of reporting the ideas and problems that were discussed in our section. I am in accord with everything that was reported.

I do believe that those of us who are in family practice would be very anxious to see these proposed plans implemented in some manner and would be most cooperative with such an effort.

DR. WEDGWOOD: I was delighted to hear your talk, particularly the emphasis on flexibility. I would like, first, to emphasize more strongly the need for direct

support of educational programs, at the undergraduate, graduate, and the continuing level, for physicians and for paramedical personnel. We have had a great deal of difficulty in supporting this type of education over the past few years.

Next, medical schools and regional centers have got to become involved in providing the training for first line or family physician care. Otherwise, we are left in a situation comparable to that of having departments of theoretical surgery, in which no surgery is done.

Finally, we have to look very directly at the need for funds for construction of appropriate facilities within which to provide the type of teaching that is necessary, in centers that are designed for the care of ambulatory patients.

If funds are not made available to provide optimal teaching facilities, as well as to support teaching personnel and educational processes, we will find it very difficult to provide the manpower that will be necessary to carry out the purposes of this meeting.

DR. POLLEY: I want to thank all of the discussants for their comments.

Clinical Investigation and Training

Chairman: John L. Decker, M.D.

The assigned task of our panel was clinical investigation and training. This is not an easy area to report on to an audience of this type. What we attempted to do was to have a look at the clinical investigation that is currently going on that is of the type that we believe pertains to the prevention of disability from arthritis. As we went through this rather large mass of material, we tried to spot areas in which we believe deficiencies exist. We ended the discussion with a consideration of the investigator himself. We did not formally vote or spend too much time on formal recommendations, with the exception that the Chairman has attempted to bring a consensus in that regard, which I will present to you at the end.

We defined clinical investigation of arthritis as the study, in the broadest perspective, of the biology of disorders that affect joints and related structures. Such study requires an interdisciplinary approach and must include, among its pur-

poses, the definition of disease, efforts to discern their etiology and natural history, and continuing analysis of their management, with special references to the prevention of disability.

The clinical investigator was described as a physician who is committed to the understanding of a disease or to the understanding of a group of diseases of man. The tools that he uses, the training he may bring to bear, and the level at which he elects to work were all thought to be less pertinent to his effectiveness as a clinical investigator than is his commitment to a disease area.

This approach to clinical investigation has produced an abundant and diversified body of knowledge in recent years. But the emphasis has, for a variety of reasons, been on fundamental studies of biochemical, immunologic, and morphologic aspects of disease. Support for these studies has been available and should continue to be available. In the long run, they are of the utmost significance.

Nevertheless, there has been some tendency for these fundamental efforts to overshadow clinical studies, to preempt the attention of investigators, junior and senior alike, and, thus, to inhibit work that

is more directly applicable to patient needs and to the prevention of disability.

The Workshop felt that both spheres are worthy of full attention. However, the charge to the Workshop was interpreted to be a consideration of clinical investigation that is directly pertinent to the patient. And this was the area to which we confined ourselves.

The inadequacy of clinical work and planning, which is currently to be noted at some of our better medical centers, was said to be evident in the poor quality of applications for support of outpatient, or ambulatory, investigative efforts, in which new techniques and new approaches are greatly needed. It was felt that the excellence of current, short-term, inpatient, acute problem studies had not been duplicated, nor even approached, in outpatient work with chronic disease, such as the rheumatic diseases.

The Workshop turned to a discussion of examples of problems that were suitable for this type of study and of some of the factors that make them difficult.

It was felt that the definition of the rheumatic diseases would require the recognition of specific disorders in their earliest phases, prospective epidemiologi-

cal analysis of genetic and environmental factors, and the setting up of diagnostic criteria. The American Rheumatism Association diagnostic criteria for rheumatoid arthritis were cited as a tremendous advance; and it was noted, with approval, that groups are now working on criteria for gout, systemic lupus erythematosus, and juvenile rheumatoid arthritis. The need for constant revision and updating is apparent and should be done systematically. Efforts to evaluate the criteria, one-by-one, should be fostered; and the results should be incorporated in updated criteria.

The imperfection and imprecision of some of our clinical methods were discussed. And pleas for standardization were heard. This is especially needed in terms of standardizing serological testing in rheumatoid arthritis. But there was also noted to be diversity and disagreement in regard to such mundane matters as the measurement of joint motion or the grading of joint damage by X-ray.

There was much interest in the role of epidemiologic studies and in the definition of these diseases; and the conclusions of the National Foundation Center Conference of 1964 were cited in this regard. Population studies have been of two types.

First, the one-time study of the population, which is designed to obtain prevalence figures, as well as information about geographic or familial aggregation of cases; and, secondly, the continuing study, in which all the inhabitants of a carefully selected area or community are repeatedly studied; for example, biannually, over many years.

Prevalence studies in some of the temperate zones of the earth have not revealed striking divergencies in the frequency of rheumatoid arthritis. It was thought to be desirable to apply the same survey techniques to areas that represent greater extremes of climatic range. Some believed the disease, rheumatoid arthritis, to be uncommon or, perhaps, absent in tropical areas.

The continuing type of study that provides information on incidence, as well as on prevalence, permits the earliest type of casefinding, and, thus, the best information on environmental factors that surround the onset of the disease. And, later, it will allow the correlation of early and minor signs and symptoms with the eventual progress and outcome of the disease.

Such studies do, of course, have their problems and limitations. The rate of

attrition, that is, the rate of emigration from the geographic area, constitutes a problem that may be surmountable with the use of some form of national registry. There is some evidence that the mere surveillance of chronically ill people may alter the disease patterns to the extent that the validity of the results is impaired. Finally, such work is costly, perhaps too costly when evaluated on the basis of the useful facts that are obtained per dollar spent.

The Workshop group felt that there was a place for the clinician in studies that are designed to determine the cause of rheumatoid arthritis, although it was granted that this is an area of strength for the fundamental or exclusively laboratory worker. The observer who is concerned with etiology of cause must always be aware that his observations may bear only on a mediating factor, important in itself, but, possibly, distinct from the ultimate cause or causes.

The discussion, here, centered on the study of events that surround the onset—that is, the period of transition from health to disease. Data are needed on such factors as time of year, physical activity, presence of a deficiency state, intercurrent infections, and the possibility of exposure

to toxic, environmental factors, such as air-water pollutants.

This kind of study is greatly improved by the ability to study prospective patients—people who will get the disease. This is possible in continuing population studies, but it involves the examination of a thousand normal persons in order to have prospective data on four or five future patients. The data, which can be practically recorded on the one thousand, must, obviously, be very limited.

We would be in a better position if such studies could be carried out on susceptibles—if there was a way to pick out, for example, one hundred normal persons, with the certain knowledge that even ten or five percent of them would develop arthritis.

There is no way to do this. But it was pointed out that the selection of susceptibles and their subsequent study could be based on a hypothesis under test. If the hypothesis were genetic it would be well to analyze mono- and dizygotic twin pairs. The available evidence hints that concordance is so low in identical twins as to cast substantial doubt on most genetic hypotheses. Blood relatives of families with two or three victims of rheumatoid arthritis might be studied, although it is possible

that such groupings should, at the outset, be regarded as an atypical form of the illness.

If the hypotheses involved infection, perhaps the spouse of the rheumatoid arthritic should be studied. If one's hypothesis involved trauma, persons who are subject to the form of trauma that is involved should be evaluated prospectively.

The next point in this matter concerns the problems of educating the public. It is to be noted that all of the above work requires a high degree of cooperation from perfectly healthy people who, particularly in a poorly-informed society, may flatly refuse the pertinent examinations.

From etiology, the Workshop turned to a consideration of the natural history of the disease, rheumatoid arthritis. This includes the study of its long-term evolution, with a view to achieving more reliable prognosis and, thus, more reliable evaluation of remedial measures that are directed toward the prevention of disability. It was believed that the medical world is now, more than ever before, capable of handling truly vast amounts of data with machine methods. This means that correlative patterns can be sought with incredible speed among the several hundred variables

that might be recorded. Stated simply, it may become possible to say, for example, that if joints A and B are active in a 35-year-old woman with an elevated sedimentation rate and a positive rheumatoid factor test, there is a ninety percent chance that joint C will be involved within the next six months.

The example is crude, but some of the Workshop felt that the possibilities thus opened are infinite. Obviously this kind of prediction is not possible until we have stored in our machine's memory the pertinent data on a rather considerable number of 35-year-old women with elevated sedimentation rates. And there is the rub. We need a massive, persistent, and painstakingly accurate data collection system. Surely, such an effort should involve many clinics and, thus, we again run into the problem of standardization—of standardizing the data to its most trivial detail. No amount of fancy computer technology can give good answers from sloppy clinical observations.

The maintenance of interest, the assurance of accuracy, and the persistence of the examiners are all problems. But the Cooperating Clinics Committee of the American Rheumatism Association has

shown us that these ideas are not visionary, that the work could be begun now. There are objections. The individual investigator feels that he is giving up some of his freedom and initiative, often precious to him. And that is true; he would be. There are advantages. Many have found that in conducting work of this kind in their clinics, the result has been a sharp upgrading toward clinical excellence for all patients, not just for those under study.

One of the thorniest clinical problems in the field is in reference to psychological factors. These may play a role in producing the disease. Certainly, they modify the degree of disability that results from it. And they are, in turn, themselves greatly influenced by the morbid process.

The control of this factor in clinical investigation has not been achieved. Several studies were cited. It has been found impossible to predict, on the basis of an extensive series of pain perception and psychological tests, which patients will do the work that is required in recovering from knee surgery and which will not. Efforts are now being made, prospectively, on the basis of monthly interviews, to determine whether or not a patient's mood has an effect on the flaring of disease activity in

systemic lupus erythematosus. Studies of this type are very much needed.

It was pointed out that the kind of physician that is required (someone with training in psychiatry and in rheumatic disease) is in short supply. Until supply more nearly reaches demand, it was the feeling of the group that extended and detailed evaluations of a few patients, with attempts to understand the processes that are involved, were more appropriate than were the more superficial survey types of analyses of many patients.

The final form of investigation that was discussed was that which directly pertains to the prevention of disability. It was pointed out that disability usually has at least three elements—psychological, constitutional, and that which is due to changes in the muscular skeletal apparatus, specifically, the joints or local damage.

Again, the work of the Cooperative Clinic Committee of the American Rheumatism Association was cited as having provided a standard of uncommon excellence in trials of medications that are directed toward reducing inflammation and constitutional signs of activity.

The lack of controlled work in the use of splints, heat, exercise, braces, and like

modalities was noted. Despite the regular observation of short-term improvement with such treatment, it seemed pertinent to suggest that long-term results should be evaluated critically.

The problem of suitable controls in surgical therapy was touched upon. No easy answer is available; but it was pointed out that detailed knowledge of the stages of progressive disease of the knee, for example, could be used to project a probable outcome, and that the result of surgery could be compared with this hypothetical outcome.

One of the major factors that restricts study of the effects of physical and surgical modes of therapy is the lack of investigative bed space. Such studies require extended hospitalization, and this key factor is simply unavailable in the amount that is required.

Three types of important inpatient facilities were discussed. It was considered mandatory that all three be in or near the center of investigative work. A few beds providing maximum services for acute, severe disease, are needed. These would be the most expensive type of general hospital beds. There is a need for more beds that provide the level of services that are

required in chronically active rheumatoid arthritis—a middle price range facility, perhaps. The least costly beds would be those in which there could be a considerable degree of self-service, but in which physiotherapy and occupational therapy would be available. It was estimated that a group of four or five active investigators, working together on problems in management, could appropriately use between fifteen and twenty beds for the investigative program, alone.

The final hours of the Workshop were spent on a consideration of the man who is to do all of this investigating. What must he be?

It was felt, first, that he must be a well-trained physician, that we can't take a shortcut and drop out portions of current curricula. He must be a complete physician, but his specialty interest or training is not necessarily pertinent. He must have interest in these problems. He must have interest in patient care, in clinical investigation, as we have talked about it, and in teaching clinical methods.

Where are we to find such a person? In this regard, it was felt that this field should face the fact that we are in a rough recruiting fight for the interest and capaci-

ties of these men. There are other programs, other areas of interest, other areas of, perhaps, more excitement; and unless we face this fact we are going to fall short. We felt that one of the ways to approach this was to work out a program, a training program, a recruiting program, with appeal to it.

We felt that it was worthwhile to establish and maintain contact with prospective trainees, beginning early in their medical career—the first and second year of medical school, for example. We felt it worthwhile to encourage summer research projects for medical students and to be able to support them. All of us wanted to inject excitement and challenge into the work of our units. We wanted to keep the program wide and flexible, so that a man could find an area of interest that coincided with his own within the overall work of the program.

Money was considered. This is a tough program. We don't simply want to buy the man. Such a person is not what we want. And yet these young men come along at a time when their needs are great. In many instances, they are deep in debt for their medical education. And there were some in our panel who felt, very strongly,

that, under certain selected circumstances, money should be available for the support of residency training. Men do not ordinarily enter a special investigative area, such as the rheumatic diseases, until they have completed two years of residency. It is very common for us to find able young men who simply do not have the financial wherewithall to manage two years of residency. Support for those individuals is needed.

Another point in the problem of recruiting is what is the future, in terms of jobs, for this individual? What does he have to look forward to? It was felt that if there were a clear picture of how and where he was to apply his prospective skills, the recruiting effort would be improved.

Next, we turned to the matter of training this individual. And here our ideas paralleled many of those that Dr. Polley has brought out. It was felt that the training would have to be largely preceptorial—simply watching someone else do it or being closely associated with someone else who is carrying on investigation. It was felt to be wrong, however, to insist, exclusively, on the preceptorial method and, thus, to disregard a more formalized ap-

proach to such problems as experimental design and biometrics. It is crucial that studies be designed with knowledge that is not generally available to the average physician. In this area, there are statisticians and specialists in experimental design who have much to give. The provision for such people, available to the trainees, was felt to be crucial.

The possibility of rotations to other services of the university was discussed. If the training program is under the aegis of the department of medicine, for example, it seems quite obvious that the trainees should have some time in connection with orthopedic surgery and in connection with physical medication and rehabilitation services. The possibility of rotation to other units across the nation, especially those providing special skills, was also discussed. Some felt that this kind of move would have to be for at least a year if it was to be worthwhile.

The possibility of providing special courses in connection with the Rheumatism Section of The Arthritis Foundation (formerly, ARA) or with other national meetings for the young investigator in training was discussed. In the last analysis, however, we felt that the most impor-

could be brought to bear on clinical investigation; and (c) clear and forthright support of clinicians of proven capacity who are in a position to give and to teach excellent patient care and to conduct clinical investigation. Such support is deemed appropriate for both medical schools and for large voluntary hospitals.

The Workshop believes that support for personnel in these three areas would greatly enhance the quantity and quality of investigation that is directed toward the prevention of disability from arthritis.

It is also recommended that careful and thorough consideration be given to the great need for bed services in investigative programs in arthritis.

Finally, it is recommended that the present law pertaining to research training grants be redrawn to expand support to include the training of teachers and physicians who are concerned with patient care as a research and teaching activity.

Discussion

HELEN ANDERSON: I would like to say that I thought this was an excellent report; and I am delighted to see emphasis on clinical research. However, just as we recognize that the patient needs many

workers other than the physician in order to be treated for his arthritis and to meet all the problems of the patient and the family, I would like to say, for all of the associated personnel, that I was a bit disappointed to hear only physicians included in the section on clinical investigation. I suggest that there is much research that those in the associated professions can do to contribute to meeting the problems of the arthritic patient.

DR. DECKER: I think that that is an excellent suggestion, and I really do feel rather apologetic about it. We have been, as Dr. Wedgwood says, parochial; and I apologize. I don't think that there was a physician in the group who had considered the possibility of attempting to carry out a clinical investigative program without the support of all associated personnel. But I also feel that there is a great breadth of opportunity for each of these groups, social workers, occupational therapists, and so forth, to run their own studies, not "managed" by a physician, in any sense. There is a tremendous need for that kind of investigation.

DR. SHULMAN: I would like to pursue this really important feature. For those of us who are in the medical situation, I

would say that I applaud everything that you have said.

First, before getting to my point, I would like to congratulate, from the bottom of my heart, Dr. Decker, for just about the most concise and thorough resume of an eight-hour discussion that I have ever heard. There is not one single point that was brought up during our discussion that was of any importance that was omitted from his unusually competent summary.

But I would like to get to the point of the associated personnel. The associated personnel are concerned with names, to some degree. And we who were on this particular panel were trying to do the best with the extremely difficult problems that we knew something about.

I know nothing about the social service aspects of arthritis. And the reason I know nothing about the social service aspects of arthritis is that, in spite of repeated efforts to obtain such services, and in spite of being in an optimal, from a relative standpoint, situation with respect to it, I don't feel true cooperation or interest from the parent organization of some of these paramedical personnel. And I would like to support, in the most general manner and, really, in the most construc-

tant element of the training is something that we already have before us, the research training grants program of the National Institutes of Health. This program has been modestly successful in turning out the kind of clinical investigator in which we are interested. However, its emphasis has been overwhelmingly on fundamental, basic investigation.

I have indicated, and others have, too, that there is nothing wrong with this, but that this is not all that is needed. The group felt, very strongly, that so long as the emphasis persisted to be confined to this area, we would be failing in the training of clinicians, clinical teachers, and people who are interested in clinical—by that I mean bedside—investigative work. We think that a better framework for the future can be built by a modification of that program.

Finally, we dealt with the question that was originally raised in considering recruitment, of where this investigator would go. Where would he work? Here, it was felt that the medical schools can, and should, consume—I guess I can use that word—can consume a number, a large number, of these individuals. When we face the fact that very few of our schools

are actually involved in any teaching in reference to this area of disease, that is particularly apparent.

The opinion was also expressed, however, that such people are needed by voluntary hospitals. Here, I am thinking of some of the excellent, topflight, large voluntary hospitals, which are gradually swinging, in many instances, to a more full-time system. It was felt that these were most suitable places for centers of excellence in arthritis and that this type of investigator could take a full-time position, under those circumstances, if support was available.

I come, finally, to the recommendations. First, it is recommended that a research committee be formed on a national basis. This body would be envisaged as including two or three full-time physicians who do nothing but serve this unit. At least one member of the full-time group should be an epidemiologist. Another might have special interests in information and data handling. The duties of this committee would be to coordinate and assist the work of those investigative units that were interested in cooperative clinical work, of any kind, in the rheumatic disease field.

Among the services that the committee

would direct would be the provision of standardized sera to be used in controlling laboratories across the Nation, the maintenance of such national registries of arthritic patients as were deemed appropriate, the maintenance of a drug information service, which would be kept instantly up to date by a standardized reporting system, and the maintenance of epidemiological data that would be in parallel with information that was available on regional facilities. The latter function would prepare the committee to advise regional university and local medical groups of unfilled needs and opportunities.

Next, it is recommended that the funding of the type of investigation that has been surveyed here be on a competitive basis with like clinical studies, but not in competition with fundamental or laboratory studies.

It is further recommended that support for personnel be given in the following three areas: (a) Relatively small amounts for support of promising house staff physicians who would, otherwise, be financially unable to complete the required training for investigation; (b) provision for suitable biometrical staff in those institutions in which the skills of such individuals

tive manner, the notion that much needs to be done at the home office. And much really does need to be done. You should plan to return from this meeting and go to your national organization, as we will be going to our national organization, with these recommendations—and I mean your national professional organization—to try to help stimulate the provision of the assistants that we sorely need to carry out our job.

DR. REDFORD: I would like to mention a point that was brought up in the discussion, particularly since it was a thought of mine: A physical therapist should participate in studies of arthritis and of some of the therapeutic modalities that are used in the area. I think that this is very important, because the motivation of physical therapists who have interest in areas other than just patient care can, perhaps, be greatly enhanced if they are used in programs in which investigative work is being done. They will go on even further, perhaps, into other fields, such as physiology and so forth.

I would like to state, for the record, that we are most interested in stimulating this kind of activity among paramedical personnel.

DR. STILLMAN: I think that Dr. Shulman made a very good point about the encouragement from the home office. But I think that even more important is encouragement in the individual unit in which the paramedical personnel are working.

Our social worker, in the unit that is associated with the study of children, is coming out, shortly, with a paper that was the result of her own endeavors. She was helped out by the other members of the group, just as every member of the group who comes out with a study is helped by the other members. But I think that they need encouragement to do this.

DR. TOONE: I would like to speak to one point in your report, and that is the part that deals with altering the training grants that are now offered by the National Institutes of Health. I think that this is a very important point, a very strong point, and I think that this should include the words "clinical traineeship." I think that, in many ways, this already is being done. I think that this would rectify the situation that is already in existence.

Furthermore, I think that this would aid us in our recruitment of new men. Some of these people are frightened by the term "research"; they feel as if they have to

take an entire laboratory training.

DR. DECKER: This is exactly the view of the group that discussed the matter, Dr. Toone, especially that point about being frightened. There is some feeling abroad that, unless you know about messenger RNA, you are just not there. And that, we would like to discourage.

DR. WHEDON: I would like to know where to begin. But I think it is important for me to try to tell you that not only do we have the authority, within the laws and regulations that govern our training grant procedures and activities, to do the things that you recommend, but we, in fact, heartily support, the fact that, and try to make that support as clear as we can, training grants for research, which does, most definitely, include clinical investigation. And there is no regulation against the inclusion of careful and detailed clinical care and clinical management as an integral part of a training grant for research.

Now, I am really disturbed about this because, obviously, we have not gotten this point across clearly. And we must go back, and we must apparently rewrite our pamphlets and our handouts and revise our telephone messages to make this per-

fectly clear.

Investigation at the bedside of indices of variation and change in clinical disease is clearly within the realm of what can be supported and is actively being supported, certainly in other fields of clinical medicine and, I believe, in some of the training grants within this area.

But please do not go away with the idea that there is some rigid barbed wire fence around the training grant programs of the National Institutes of Health or of the National Institute of Arthritis and Metabolic Diseases that excludes active investigation of the patient, as supported by our training grant programs.

DR. DECKER: Thank you, Dr. Whedon. I think this is very well and very fairly said.

The recommendations are probably written too much in terms of legalisms. To some extent, this is a matter of the mind, a state of mind, or a frame of mind for which no particular person or body is responsible.

DR. GLENN CLARK: I realize that everything that Dr. Whedon says is true, and I am not sure that it is the fault of the law or of our attitudes that programs for clinical investigation don't become better

funded. I think that the reason is probably, as was mentioned, that of having clinical programs compete with basic science programs. It is very, very difficult, in this newer field, to design a clinical program that looks as nice on paper, that has as good controls. In rheumatoid arthritis, for instance, they ask, "Where are your controls? How are you going to get a patient with rheumatoid arthritis who doesn't go down to the drug store and get aspirin?"

I would like to have the study committees look a little bit more into some of the new and, perhaps, less stereotyped ideas for clinical research. I would like to see them put a little seed money into, perhaps, a different and less well-organized, at first, approach to clinical investigation. Above all, as you mentioned, these grants should not have to compete with basic science grants in the study committees. That is extremely important.

DR. FENNINGER: It seems to me that through all of the presentations and discussion, one recurrent theme has come up: advice, education, and recruitment. And I think that part of the dilemma that we all face has to do with the piecemeal way in which we have approached the whole ques-

tion of health care, of rendering health services, of research in the various fields that are related to health, and of the support of education and the support of residency programs and postdoctoral traineeships. It seems to me that the time has come to decide what the fundamental issues are.

The first issue, I think, is the general support at the undergraduate level of education in the health professions. I was very glad to hear Dr. Polley mention this in his report; and Dr. McEwen, I think, mentioned it in his report.

Second, the exploration of the range of investigation in the clinical field, which, I believe, is as fundamental as is dealing with molecules or portions thereof, requires, in our present cultural setting, some kind of general support of research within institutions that are designated by the members of the institution.

So, it would seem to me that there should be fundamental support of education at the undergraduate level. And there should be fundamental general support of research at the institutional level, in addition to the other mechanisms that we now have, such as the programs and projects that are supported on a national basis in national

competition. But while I think that it is extremely important that we retain present programs and projects, I think that they need a much broader foundation in the support of education and in the support of research at an institutional level than is now provided.

I think both science and society demand that we reexamine the bases of support and put them in their proper perspective.

DR. WILLIAM CLARK: I will make it brief.

There is a very fundamental problem here. You stressed in your report, Dr. Decker, that it will be necessary to collate or integrate a vast amount of clinical observation, that the basic problem we have is in collecting reproducible observations by standardized criteria.

Now, we know that it is a fact that these observations on the patient are going to have to be made by a clinical observer who will not be supported as a fellow, committed to clinical investigation. In practice, in most instances, these men go off into a clinically-oriented career that is devoid of investigational opportunities. This is a basic deficiency and many of us know the policy of the National Institutes of Health very well; and we know that these fellows

will not qualify for fellowships, nor will their projects qualify for research grants in clinical investigation. It is a deficiency that we must make up, or the observations that we are making on rheumatoid disease will always be garbage.

DR. BLAND: It seems to me that, because so very much has been brought together at this meeting, we are about to get off the ground. Since the gears of government shift slowly, I suggest that all of us make known to our Senators and Representatives the conclusions of this meeting, in the next few weeks, rather than at a later time.

DR. SHULMAN: Just one plea. After hearing the comments of Dr. Whedon and, then, of Dr. Glenn Clark, I would only make a plea. Tremendous gains have resulted from the quality of the efforts that have been engendered largely through the support of the National Institutes of Health and The Arthritis Foundation, and we, in extending our efforts to clinical training and recruitment, must insist on the same quality. I don't think this has been emphasized.

The danger exists that because of the demands of the public for increased efforts in this area, we may risk the irreparable damage of impeding our actual goals by

not insisting on the type of quality control that should be exerted.

DR. LAMONT-HAVERS: Dr. Decker, I should like to second that. There is no sense in just training or in just giving grants in clinical investigation or in supporting people for clinical medicine. You have to look at the product. You have to look at the trainer. And I think that much of the lack of support or the suppression or taking away of support at the present time is not due to the fact that this type of investigation cannot be supported; it is the product that is being turned out that is not worth the support.

DR. DECKER: I think that is pertinent.

MRS. KINOY: I just wanted to speak briefly on what some of the other people, earlier in the discussion, talked about, and that is this question of the team approach to basic investigation. I think that we have come a long way toward the use of many different kinds of paramedical personnel, or whatever we wish to call them, in working out followup and long-term care of patients with arthritis. But I don't think we will be able to attract people from many other disciplines to work in this whole area of arthritis unless they feel that they are in on the ground floor of planning the basic

kinds of community research. And for this reason I think we have to make a special plea to include them in this whole area of research.

DR. CLEVELAND: I want to wish you God Speed in your search for this superman in research that you outlined in your background paper. If you don't find him, there may be some models that are already available that will be of help, especially in the area of investigating psychological research and of investigating psychological factors in arthritis in various parts of the country, where psychologists are already collaborating with rheumatologists and pediatricians in this area with some degree of success.

In California, I think, there is a psychologist by the name of Rudy Moos who has done some work recently with Dr. Engleman. In Boston, Dr. Stillman's group is working in this area; and in Houston we have something going. We do have some communication among the psychologists who are involved in this area, and I think we might be able to offer something, here, in terms of a group that is already working in this area who have some communication among themselves.

But I think, in terms of responding to

Dr. Shulman's earlier remarks about this, that the psychologist will need an invitation from the medical people who are in the field who are administratively responsible for these positions. The psychologists are very busy people, too, and I don't think that they will spontaneously become involved unless they are invited.

DR. DECKER: None of my remarks should be interpreted to mean that we are trying to exclude anybody by training one person to do everything. That is obviously ridiculous.

DR. BLAND: I am concerned that we are creating the impression that a clinical or a patient-oriented investigator is very different than a basic investigator in medical sciences. They are all the same people. And I wager that there is no one in this room who doesn't have a basic program, meaning one that is wholly non-patient oriented. I work with a colonizing amoeba, and I relate it to the bedside physician.

I certainly wouldn't want to come off with the notion that the bedside doctor is a very different person than is the precipitator of proteins, because he really isn't.

Voluntary and Public Agency Activities and Programs

Chairman: William D. Robinson, M.D.

Our Workshop, which is concerned with voluntary and public agency activities and programs, had representatives from agencies that perhaps were not as well represented on other panels. Not only did we have the formal health departments represented at the national, regional, state, and county levels, but we had representatives from the Council on Voluntary Health Agencies of the American Medical Association, one individual who was concerned with professional relationships in the Blue Cross Association, and representatives of the Visiting Nurses Association and the physical therapy fields.

Our Workshop started off with the following premises: That we could regard rheumatoid arthritis as the prototype for the development of a program that would automatically include other crippling diseases, and that prevention of disability in rheumatoid arthritis could, quite clearly, be related to the institution of care early

in the course of the disease and to the provision of continuing medical and social support.

We started by visualizing the course of a hypothetical patient with rheumatoid arthritis, with an attempt to project the stage in the evolution of the disease that brought the patient into meaningful contact with the programs of the various voluntary and public agencies. Intertwined with the review of the current status of such activities was emphasis on what can be done to bring these efforts to bear more effectively on the patient in the prevention of disability.

Much attention focused on the mobilization of present and potential activities, so that they can be brought to bear on the patient earlier in the course of his disease. This broke down into several components, the first of which covered efforts to decrease the interval between initial symptoms and the first medical contact.

We have chosen to use the term "first contact physician," or "first medical contact," rather than "general practitioner" or "family practitioner," because, in realistic terms, the first medical contact and the personal physician may frequently be an internist, a pediatrician, an obstetrician, a

surgeon, or a man in any other field of medical practice. Decreasing this interval is, quite clearly, a matter of public information and interest—an area in which the recommendations of the first panel become particularly important.

The second point centers on efforts to make this first medical contact more effective in leading the arthritis patient to prompt and adequate care. This involves the basic training of the physician, which has been discussed eloquently in previous panels. It also involves the post-graduate educational effort that must be made if the practicing physician is to be kept up-to-date in the field of arthritis. It implies the availability of resources for early and accurate diagnosis and the availability of facilities for the provision of total, or comprehensive, medical care that is adapted to the needs of the individual patients.

Some patients may require referral to an arthritis center, in order that special skills and resources can be brought into operation. Others can be adequately cared for in the local community. But it is important, here, that the community resources be brought to bear early in the course of the disease, rather than later, as is too often the case at the present time.

A third point dealt with the problems of providing early and adequate hospitalization for the arthritic patient and with the adequacy of hospitalization, in terms of both duration and quality of care. Often, an initial period of hospitalization can be provided in a community or general hospital. Such hospitalization provides an opportunity to bring to bear on the particular patient the following principles of treatment: Rest; adjustment of medication to the needs of the particular patient; application of mechanical principles and devices to prevent deformity; indoctrination of the patient in the use of physical therapy to maintain function; and careful attention to all the factors which can exert a deleterious effect on either the physical or psychological health of the individual. We were not particularly enthusiastic about the so-called "halfway house," as the facility in which the initial activities in management of the patient with rheumatoid arthritis should be carried out.

A period of hospitalization also serves most effectively to educate the patient about the nature of his disease and to introduce him to the essential features of his long-term care program.

The fourth component dealt with the

provision of continuing medical and social support for the patient. This is the area in long-range care that brings the physician who is concerned with prevention of disability into contact with many agencies that have a responsibility in the area of chronic illness—a responsibility that is not focused exclusively on the patient with arthritis. At the present time, such continuing support is seldom brought to bear until relatively late in the course of the disease. The groundwork for such support can often be laid during the initial period of hospitalization. But such support can, and should, be applied when appropriate, soon after the first medical contact.

The principal ingredients of this program of long-term care are continued surveillance by the physician, aided by the home care program, as implemented by visiting nurses or public health nurses, supervision of the physical therapy program, and utilization of the aid of social service workers, dietitians, and vocational, occupational, and recreational therapists, when appropriate.

In the course of reviewing the current activities of public and voluntary agencies, it was apparent that several are concerned with public information. This is a major

activity of The Arthritis Foundation, both at the national and chapter levels; and the Foundation has been active in the preparation and dissemination of authoritative information on arthritis. It has also been a concern of the Public Information Service of the American Medical Association, the Division of Chronic Diseases of the U.S. Public Health Service, and their counterparts in the State and local health departments.

Patient education, as distinct from public information, is also a major function of The Arthritis Foundation, which not only provides pamphlets for patients with various types of arthritis, but, particularly at the chapter level, functions as an "information, counseling, and referral service." Patient education is also an objective of the Patient Information Service of the American Medical Association.

In considering professional education, members of our panel also pointed out deficiencies in the opportunities for medical students to experience exposure to the problems of chronic diseases, including arthritis, to participate in long-term care of patients, and to become familiar with the community agencies whose resources must be brought to bear in the management

of such patients.

In postgraduate education, several organizations are concerned with the effort to keep the medical practitioner up-to-date with respect to advances in diagnosis and management of rheumatic diseases. This is a place where the Rheumatism Section of The Arthritis Foundation (formerly, American Rheumatism Association) certainly takes a major role. It is also the concern of the Committee on Continuing Education of the American Medical Association's Council of Voluntary Health Agencies, which is particularly concerned with improving the effectiveness of the "first contact physician."

With respect to the training programs of the National Institutes of Health, it is correct to say that they are not in a position to support training for the development of clinical proficiency. They are in a position to support training in clinical investigation and, of course, training in other aspects of research.

The problem of training the allied medical and health professions also came up for consideration. We appreciated the problems of recruitment and of support. We did feel that a very worthwhile function was served by symposia, frequently

sponsored jointly by chapters of The Arthritis Foundation and by public health agencies, to provide public health nurses, visiting nurses, nutritionists, physical therapists, social service workers, and vocational, recreational, and rehabilitation workers with information regarding the particular needs of the arthritic patient; and we felt that some arrangement for short-term training programs of a few weeks or more for such individuals, with attention placed on the needs of the arthritic patient, would definitely be worthwhile.

New to many of us was the matter of therapeutic recreation, with the objective of maintaining the handicapped individual as an active participant in society. This addition to the community agencies that can be brought to bear on the long-term management of arthritic patients was explained to us by the representative of the National Recreation Association. It has been demonstrated that, in cooperation with the responsible physician, arthritic patients can be included in regular recreational programs, that recreational programs can aid in getting the homebound arthritic back into community activities, and that such recreational activities can be success-

fully coordinated with nursing home programs.

There are two or three somewhat disjointed points that came out in our panel discussion that may be of interest to all members of the Workshop.

It was the public health officers in our panel who pointed out that, although the magnitude of the problem of arthritis made it a public health problem, it could not be realistically approached by "mass methods," in either diagnosis or treatment. The diagnosis of arthritis rests on evaluation of the history and physical findings that are obtained by the physician who is aided by X-rays and selected laboratory tests, rather than by any single criteria. Similarly, management depends not upon a single modality, but on a program that is carefully individualized to the needs of the particular patient. This is a process that obviously has to be done by the physician and can not be accomplished by mass methods. Therefore, the role of a State or local health department was visualized as a supportive one for the practicing physician, providing the resources when, and where, they are lacking in the community, for the physician to carry out diagnosis and treatment. The health departments are

also able to contribute to the coordination and development of community resources that are needed for long-term care.

Another point that is worthy of reporting is the fact that, in considering the special problems of the arthritic related to hospitalization, it appeared that agencies that are concerned with hospital insurance and medical care insurance can be expected to be responsive to the needs, both for hospitalization and for certain aspects of home care, as they are defined and requested by the practitioners in the particular community or region that is served by such insurance plans. As a matter of fact, whether we were discussing the activities of a community health department, the activities of the visiting nurses or public health nurses, or the programs of various other supportive agencies, it was brought out, repeatedly, that the most effective way to bring these agencies into meaningful activity in the arthritis field is to develop the demand for such services at the community level, by the physician that these agencies have been designated to assist and with whom they are accustomed to work.

It was interesting to note that the incorporation of arthritis as a categorical pro-

gram, a special interest program, into already existing programs presented the same types of problems in all areas—from medical school curricula to the activities of a county health department. The problem of introducing a categorical interest into a program that was already under way and integrated consisted of the usual basic difficulties—limitations of time and money, shortage of trained personnel, and competition of a new program with ongoing responsibilities, which were already overtaxing the available resources. In each instance, it appeared that the integration of activities that were directed toward the arthritic into programs that were concerned with chronic illness was the most feasible and practical solution. I, personally, do not fear that arthritis will lose its identity by following such a course. It is quite clear that arthritis can serve as the prototype for the development and focusing of resources that are needed in many other types of chronic illness.

We do not have a series of carefully enumerated recommendations. However, I find that, in some way or other, most of them have been covered in reports of previous panels.

After careful consideration, this panel

does recommend that existing programs be supported, strengthened, coordinated, and expanded to the geographic areas in which they are lacking. In contrast to the development of a new structure, we believe that building along the strengths and bolstering the weaknesses of what we now have is not only a more practical approach, but, in the long run, will be more effective.

Because, at every turn, we came up with the fact that the educational program, at all levels, would be instrumental in providing the resources that are necessary for the adequate care of patients with rheumatoid arthritis, we recommend that voluntary agencies, in cooperation with public health agencies that are interested in arthritis, spearhead a more extensive public, patient, and professional information and education program that will utilize imaginative and creative techniques. All channels of health education should be used. The Arthritis Foundation may well play a leading role in this effort.

It is our impression that the preparation and formulation of authoritative information in the field of arthritis has been well accomplished. The channels of dissemination of this information, in the form of pamphlets, brochures, and so forth, have

been well developed. But the primary problem is one of really getting this information across to the public, to the first contact physician, and to the medical student. The real problem is getting this information across in such a way that it has a meaningful impact.

The need for a recruitment program in the paramedical professions has already been mentioned. It was felt that recruiting in this field might well be the primary responsibility of the voluntary agencies, who are in a key position to have an impact at the time of career choices. Financing may well be an area for consideration of governmental support.

There are, essentially, two ways in which interests in arthritis can be stimulated in State health departments. One would be the addition of arthritis to the categories in which formula grants can be made to State health departments; at the present time, such grants are restricted to heart disease and cancer. The other is stimulation by chapters of The Arthritis Foundation of activities in the State health department that are appropriate to the field.

Again, as far as activities in local health departments are concerned, the stimulation by chapters of The Arthritis Foundation

would appear to be a logical recommendation.

There are grants available in the Public Health Service for planning and survey of community resources under the Community Health Service and Facilities Act. These are short-term grants that are usually concerned with efforts to decrease the need for hospital beds and hospitalization and with utilization of home care plans and nursing homes. It appears that such grants, for purposes of surveying and planning a community's resources for the chronically ill patient, could well be recommended.

I hope that other members of the panel will not hesitate to add to or modify the report as I have presented it. Thank you.

DR. MCDONALD: Dr. Robinson, I want to express my appreciation to your group for defining, so well, the appropriate relationship of the public health agencies to the practicing physicians. The people whom I think are smart are those who agree with me, but can express it better. So, therefore, I think you are a very smart man.

DR. ROBINSON: Frankly, it was an education to me to learn what the divisions of authority and responsibility at the various levels of the public health activities in this country actually are. I am impressed

with my ignorance on the subject. Perhaps this should go into medical school curricula, too.

FROM THE FLOOR: Hear!

DR. BLAND: There has been so much discussion in New York about the need for professional education that I think it may pay to emphasize, again, some of the opinion that was expressed, both here and in our panel. Frequently, what happens is that the best treatment goes to the sophisticated, aggressive, and educated patient. Certainly, one of the functions of the voluntary agencies in the field is to motivate, educate, and train patients to make maximum use of existing community health facilities. Frequently, it is not only a question of the lack of availability of facilities, but also the poor utilization, or misutilization, of facilities.

I think, also, that, in light of the kind of discussion that we have had through most of the reports from these Workshops, beginning with the very first one, with recognition that financial support is a major problem that faces the arthritis field and that with the recommendation of Workshop One and the view that voluntary agencies, in cooperation with the governmental agencies, have a responsibility to

advance the educational program on all levels, that it seems to me that it is worth thinking, for a moment, about the somewhat unique aspect of the voluntary agencies in advancing the public's restlessness with the present level of care.

The ultimate responsibility, I think, for an increased flow of Federal, State, or local money, from both public and private sources, is going to depend very heavily on an aroused public. And it seems to me that a part of the community education and public information and education function of the voluntary agencies is to arouse the public, not only to knowledge about the disease, but to a desire to see that the necessary funds flow promptly to those areas where they are needed.

MR. WARTOFSKY: In your rundown of the information distribution points, you omitted the National Institute of Arthritis and Metabolic Diseases. I do know that we have an active special education program and exhibits, brochures, and so forth. I do hope that you will include it in your report.

DR. ROBINSON: I spent a fair amount of time on that point in the background paper, and the role of the National Institute of Arthritis & Metabolic Diseases in

professional education was emphasized there. In the report, today, I attempted to bring out, primarily, those things that had not been covered in the background paper. I am sure that by proper adjustment of the two sources we shall have a more complete review of present activities.

Socioeconomic Aspects *(Financial Resources)*

Chairman: Ronald W. Lamont-Havers, M.D.

One of the most effective means of judging the profound impact of arthritis on the patient, his family, his community, and the Nation is to examine its associated socioeconomic problems.

Statistics

The extent of the socioeconomic factors that are associated with the arthritis problem can be realized by a review of the statistics that are obtained through the National Health Survey and from other sources.

Table I shows the latest estimates of the number of people in the United States who maintain, during lay interview, that they or a member of their household have aches and pains that are related to the muscular skeletal system. This figure is now 12,668,000; but when it is compared to more intensive community surveys, a total of over 13 million people who suffer from muscular skeletal complaints is obtained. This means, in effect, that 13 million people think they have, or think that members of their family have, something that is wrong with their joints or muscles.

A more meaningful figure is the one that shows that some 3,300,000 people in this country maintain, on household interview, that they have limitation of activity of some sort.

Of interest is the fact that although the number of arthritics who are over 65 years of age is less than the number who are under 65, the percentage of those with limitation is greater in the age group over 65. Limitation, therefore, increases with age. In fact, if we break down the statistic that shows 3,300,000 persons with limitation, we see that there is a great increase in the amount of limitation in the age group

over 65 and that this increase occurs particularly among the female population. These data are in Table II.

Table III shows that the arthritis that does cause limitation interferes with the patient's major activity.

It should be emphasized that these statistics from the National Health Survey do not relate, in any way, to any of the diagnostic categories of the rheumatic diseases.

This conference has pointed out, very clearly, that one of the problems in the rheumatic diseases is that of nomenclature. At times, during the deliberations of the past few days, arthritis has meant any muscular skeletal ache or pain. At other times, it has meant, specifically, the severe rheumatic diseases, or again, it has been equated particularly with rheumatoid arthritis. The statistics and discussions that relate to these three interpretations are not really comparable.

There has been a mention, today, of the need to have a registry, or some central gathering point, of all diagnoses of rheumatoid arthritis and followup information on patients. The Canadian Arthritis and Rheumatism Society has done something like this. Information on all patients who have received treatment through the So-

ciety is recorded in a central record file, in Toronto. From this source, Dr. Robinson, Medical Director of the Society's Medical Centre, was able to collect data on 10,000 cases of rheumatoid arthritis, which had been referred by physicians to the Canadian Arthritis Society for therapy, chiefly physical therapy.

The age of admission of these patients increased by decades. It peaked at the 50-60 decade. The increment of each decade was added to that of the following decade. An analysis of this shows that approximately 500 new cases are added a year. Whether this means that the incidence of rheumatic arthritis in Canada in this group is 500 a year is another matter. It may be. The dropoff after the age of 60 reflects that fact that people begin to die at that time of life; it doesn't mean that their disease is getting better.

Dr. Robinson was also able to show that the amount of disability increased with age in rheumatoid arthritis. This fits in very well with the data for all persons with arthritis from the National Survey. In Dr. Robinson's study, there was a precipitous rise, by decades, so that by the sixth decade, approximately 50 percent of all patients with rheumatoid arthritis had

major disabling conditions when they were referred to the Society.

Table IV confirms the statement that arthritis is a condition of the lower economic groups. As gross family income goes down, the percentage of arthritis and, also, the percentage of individuals in the limited group goes up.

There was some question about whether this increase was related to the age of the patient or to the fact that as the patients got older, particularly over age 65, their income dropped off. Therefore, Table V was computed. This table shows that while it is true that persons who are over 45 do have more limiting arthritis, it is also true that those over 45 years of age with family incomes under \$4,000 have even more than do those with yearly incomes in excess of \$4,000. Thus, it can indeed be said that limitation from arthritis is associated with lower income, regardless of age, although it is also associated with increasing age.

Table VI and Table VII are an estimate of the costs for arthritis and rheumatism in millions of dollars. They really represent the minimum figures, not the maximum. There is every indication that the real cost is even greater than this. Again,

this is direct cost; and it does not include the indirect costs.

The figure of \$435 million for drugs and other remedies was obtained from the report of Ruth Walrad, which was made in 1961. Included in this amount is the sum of \$250 million, which was estimated to have been spent for products that were falsely and misleadingly advertised.

The National Health Survey has done some experimental tabulation of data on arthritis as part of a multiple diagnosis. It is well known that in the older age group, particularly, arthritis is usually but one of multiple conditions. To get the true socio-economic impact of arthritis, therefore, one must consider not just those cases in which arthritis is the primary disease, but, also, those in which it is associated with other illnesses. These statistics are extremely difficult to interpret, at the present time, and discussion would not be profitable. They do present a challenge for the future, and the National Health Survey is trying to work out techniques and means by which the various multiple diagnoses on patients can be evaluated.

As far as the indications of indirect costs are concerned, they must be tremendous. The recommendation of our

Workshop with respect to a detailed study of the indirect, or economic, costs of arthritis is significant in this connection. Data are not available at the moment for estimating the indirect costs of this long-term illness. To do so, correctly, would necessitate taking into account losses in output that would range from the time of the onset of the illness. We would estimate the present value of future losses and would

Table I Persons with arthritis or rheumatism, by age, sex, and activity limitation, United States, July 1961—June 1963. (Civilian noninstitutional population)

Age and sex	Number persons with arthritis or rheumatism (in thousands)	With activity limitation due to arthritis or rheumatism	
		Number persons (in thousands)	Percent of total
Total	12,668	3,300	26.0
Under 65	7,661	1,641	21.4
65 and over	5,009	1,659	33.1
Males, total	4,400	1,202	27.3
Under 65	2,655	623	23.5
65 and over	1,744	579	33.2
Females, total	8,268	2,098	25.4
Under 65	5,003	1,018	20.3
65 and over	3,265	1,080	33.1

Source: Unpublished data, and chronic conditions and activity limitation, United States, July 1961-June 1963. Estimated annual average. U. S. Department of Health, Education, and Welfare, Public Health Service Publication No. 1000-Series 10, No. 17, May 1965. Washington: U. S. Government Printing Office.

compute the losses that are associated with the person, or child, who contracts the disease at an early age. We would also take into account his future losses, in terms of a spread over a period of time.

There is, however, one figure that should be emphasized. This is the number of work-loss days of patients who are usually working—12 million. This figure does not include the housewife.

Table II Percent distribution of persons with arthritis or rheumatism who are limited in activity, by age and sex, United States, July 1961—June 1963. (Civilian noninstitutional population)

Age and sex	Persons with arthritis or rheumatism who are limited in activity	
	Number (thousands)	Percent distribution
Total	3,300	100
Under 45	327	10
45-64	1,314	40
65 and over	1,659	50
Males, total	1,202	36
Under 45	120	4
45-64	503	15
65 and over	579	17
Females, total	2,098	64
Under 45	206	6
45-65	811	25
65 and over	1,080	33

Source: Chronic conditions and activity limitation, United States, July 1961-June 1963. Estimated annual average. U. S. Department of Health, Education, and Welfare, Public Health Service Publication No. 1000-Series 10, No. 17, May 1965. Washington: U. S. Government Printing Office.

In reality, these statistics can give but an indication of the problems. A great deal more information is needed if a better delineation of areas for greater concentration of efforts is to be obtained. What can be done, and what needs to be done, is shown very effectively by the background studies in the economics of heart disease, cancer, and stroke, which were prepared prior to the DeBaKey Report.

Table III Persons with arthritis or rheumatism who are limited in activity, by degree of limitation, United States, July 1961—June 1963. (Civilian noninstitutional population)

Degree of limitation	Persons with arthritis or rheumatism who are limited in activity	
	Number (thousands)	Percent distribution
All degrees	3,300	100
With limitation, but not in major activity	714	22
Limited in amount or kind of major activity	1,888	57
Unable to carry on major activity	697	21

Source: Chronic conditions and activity limitation, United States, July 1961-June 1963. Estimated annual average. U. S. Department of Health, Education, and Welfare, Public Health Service Publication No. 1000-Series 10, No. 17, May 1965. Washington: U. S. Government Printing Office.

Recommendations

It is recommended that a much more detailed study of economic costs be made, as a concomitant activity to further planning of means of overcoming the effects of arthritis.

The details of medical care could not be discussed by our Workshop. It was recognized, however, that the care of the arthritic patient represented a continuum of services that involve diagnosis, medication, and rehabilitation, with its physical,

Table IV Persons with arthritis or rheumatism who are limited in activity, by family income, United States, July 1961—June 1963. (Civilian noninstitutional population)

Family income (annual)	Persons with arthritis or rheumatism who are limited in activity	
	Number (thousands)	Percent distribution
Total	3,300	100
Under \$2,000	1,269	38
\$2,000-\$3,999	764	23
\$4,000-\$6,999	605	18
\$7,000 and over	478	15
Unknown	184	6

Source: Chronic conditions and activity limitation, United States, July 1961-June 1963. Estimated annual average. U. S. Department of Health, Education, and Welfare, Public Health Service Publication No. 1000-Series 10, No. 17, May 1965. Washington: U. S. Government Printing Office.

mental, and social aspects.

The increasing degree of disability with the length of time of the disease gives rise to the conviction that early diagnosis and treatment, with continued supervision, could limit the effects of later disability. This, of course, has been the dominant theme of this conference. Even though such comprehensive care, given early in the disease, would result in increased initial expenditures, it was our belief that this would be more than offset by the de-

Table V Comparison of persons with limitation of activity from arthritis or rheumatism with total population, by family income and age, United States, July 1961—June 1963. (Civilian noninstitutional population)

Annual family income and age	Total population (in thousands)	With activity limitation due to arthritis or rheumatism	
		Number persons (in thousands)	Percent of total
Total	¹ 181,964	¹ 3,300	1.8
Under \$4,000	56,390	2,033	3.6
Under 45 years and over	34,897	114	.3
45 years and over	21,493	1,919	8.9
\$4,000 and over	115,056	1,083	.9
Under 45 years	87,299	200	.2
45 years and over	27,757	883	3.2

¹ Includes unknown incomes.

Source: Chronic conditions and activity limitation, United States, July 1961-June 1963. Estimated annual average. U. S. Department of Health, Education, and Welfare, Public Health Service Publication No. 1000-Series 10, No. 17, May 1965. Washington: U. S. Government Printing Office.

creased need for more comprehensive and expensive services later in the disease. It should be emphasized that while this was the deep conviction of the Workshop, nobody knows whether this will, indeed, be true.

It is recommended, therefore, that studies should be undertaken to evaluate the extent to which early diagnosis and treatment would prevent, delay, or limit disability from arthritis.

Such studies should include the role of

Table VI Estimated expenditures for arthritis and rheumatism (annual).

Item	Amount (millions)
Total	\$645
Hospital care (short-stay hospitals)	\$ 60
Physicians' visits	150
Drugs and other remedies (nonprescription)	435

Table VII Estimated work-productivity loss to national economy because of arthritis or rheumatism (annual).

Item	Amount (millions)
Total	\$520
Among arthritics who work but lose time because of arthritis	220
Among arthritics who are unable to work because of arthritis and who receive disability benefits	300

early hospitalization, as one of the methods of control, of management, and of patient education.

This recommendation recognizes the need for further studies to make more feasible the early detection and diagnosis of those patients who would become disabled.

An attempt was made to arrive at the cost of disability, particularly with some estimate of the direct cost that confronts the patient with disabling arthritis. It was recognized, immediately, that these data were not available. And the advisability of making it available was incorporated into the first recommendation.

Nevertheless, some figures were arrived at that are of interest. The initial medical workup, for example, was estimated at between \$35 and \$150. This was obtained from a practicing physician. The data from the outpatient department at one volunteer hospital in New York City indicate that the average cost to the patient for the initial workup is \$100.

Continuing medical care, based on the need for weekly visits for, say, gold injections, was estimated at from \$20 to \$50 per month. Hospital costs for active beds was averaged at around \$40 a day, although there

is a wide variation in costs in this area.

There was discussion of those types of minimum care units that would cost less. This area needs a great deal more exploration.

It was recognized, by the way, that the shorter the hospitalization of the patient, the greater the per diem rate to the hospital. There was discussion as to how hospital rates were set. The multiple factors that are involved in this topic were so complicated that no recommendations were made.

Apparently, there are no reliable figures that apply to the arthritis patient who is treated in the outpatient clinic. One figure, however, was obtained from the Los Angeles Welfare Department, which pays six dollars a visit.

There was consideration of the role of the nursing home and of its changing status. With the increased services that nursing homes are attempting to give, both in diagnostic and rehabilitative measures and in other functions, there is obviously a change in rate schedules. At present, the average nursing home cost is anywhere from \$200 to \$250 a month, and this is low. It should be mentioned, in this connection, that the majority of such nursing

homes, as opposed to hospitals, are proprietary. There is an attempt, at the present time, to achieve a closer working relationship between nursing homes and hospitals, although there are many problems associated with this.

There was also discussion of home care services. This type of service, with its multiple functions, can play an important part in the care of the arthritic patient. Fifty-five percent of the population of the United States lives in areas that are supplied by such services. But less than one percent of this population actually receives such services.

Even though the need for home care services is probably much greater than we think—how much greater, nobody knows—it cannot be met because of the gross inadequacies of staff and facilities at the present time. Certainly, a study should be conducted in this area.

The average cost per visit for home care services was four dollars in 1964. This was an increase of over five percent from the preceding year. So, here again, increasing costs are associated with the care of the patient.

Arthritic patients in a Philadelphia study received, on the average, the largest num-

ber of visits of the various disease groups, including hypertensive heart disease. On the average, the arthritic patient needed 22 visits per year.

It is recommended, therefore, that means of extending home care services should be explored.

A particular problem, which should require greater recognition and further study, is that of providing household assistance. Also, of equal need are means to combat isolation and the problems of the chronically ill older person who lives alone. Further experimentation should be done with means of providing methods of contact with community resources.

The problem with the very poor is the fact that they are not sophisticated enough to seek help. An added problem with the aged is that they become withdrawn. They have ambulation problems, to which their arthritis contributes. The need for more meaningful data on community resources for these people is apparent.

The payment of medical care comes from many sources. These include direct payment; insurance that is provided by the sponsor, such as Blue Cross or Blue Shield; insurance from commercial sponsors; insurance from independent or consumer

sponsors, such as HIP (Health Insurance Plan of New York); governmental or tax supported insurance, which includes welfare, veterans, vocational rehabilitation, and crippled children programs; and, of course, Medicare.

Approximately 129 million persons, about 70 percent of our population, are covered by some form of voluntary health insurance. Sixty million persons have Blue Cross and 50 million have Blue Shield. It should be noted, however, that much of this coverage is very limited and that of those who are over the age of 65, only 50 percent are covered. In the lower income groups, coverage is even less. And insurance that is provided for these people is grossly limited for services other than those that are provided in the hospital.

The arthritic is particularly concerned with problems that occur in areas that are related to the chronicity of the disease and to treatment that takes place outside of the hospital. This applies, especially, to such things as ambulatory care, home care, rehabilitation, nursing homes, chronic beds, chronic bed care, and, in general, diagnostic services and drugs.

It is recommended, therefore, that encouragement be given to the exploration

of means of achieving flexibility of insurance mechanisms. These mechanisms should include an appropriate welding together of both public and private financing to cover the full range of care, including the home, ambulatory, hospital, and rehabilitation needs of the arthritic patient and of persons with chronic disease, generally.

It was mentioned that such a plan should probably contain a deductible clause. It could not be expected to cover everything, however, primarily because of the increased costs to the insured, in such circumstances.

Since a large proportion of all arthritic patients have inadequate incomes, there is a need for tax support to cover a full range of care for many patients. Among plans to provide this support is H.R. 6675, the pending legislation for health insurance for the aged. If this legislation is enacted, it may be helpful to the aged section of the economy. But it will not solve all of the needs of the chronically ill patient. This brings up the question of how much of the gross national income can be allocated to health care. Of course, nobody knows. At the present time, approximately six percent of our gross national income does go into some form of health care.

This is much higher, as a matter of fact, than it is in such countries as England, where, even under a socialized medicine scheme, four percent is spent.

It is assumed that in a society as affluent as our own more of the gross national product could be spent on health care—perhaps, up to 10 percent. This, of course, would depend a great deal on other factors, such as expenditures for defense. It was believed that there should not be fragmentation of the provision of health and welfare services by disease or patient pedigree; rather, there should be collaboration of a sort that would lead to coordination of health services, where geographic location is the determining factor.

It was pointed out that, at the present time, a social worker really needs an advanced college degree to comprehend and manipulate all of the many “ifs, ands, buts, and maybes” that he encounters in the various services that are offered. The patient must be either blind, but not lame, deaf, but with no gastric ulcers, Presbyterian, but not United Church, or one thing, but not another, if he is to qualify for care.

There is an obvious need for coordination, and there are many channels through

which it can be achieved. It may be brought about by one of many organizations with a wide interest in the community. These include the community health welfare councils, hospitals, and local health departments.

It is recommended that further study and exploration be given to the matter of making the extensive health and welfare services of the core, or central, community available to the satellite regions for purposes of forming a coordinated and cooperative program.

It was pointed out that health services are frequently stopped at city boundaries, which, in the modern organization of urban areas, have little real meaning.

Such available services should include a wide range of treatment and care disciplines, including physicians and associated professions—volunteer health and welfare agencies, hospital and related institutions, and governmental agencies, including public health and welfare departments and vocational rehabilitation services.

Health services should be included under the present antipoverty campaign. At the present time, health services frequently are not even considered in this campaign.

The Workshop ranged over a wide va-

riety of topics. They did consider one final recommendation:

It is recommended to the Surgeon General that arthritis be recognized as a major health problem to the Nation that warrants a concerted effort to overcome it by all available means.

Discussion

DR. REDFORD: I really appreciate this report because I think it reveals a lot of things that I may have had questions about for a long time.

One point you made, though, that you did not have any figures on the cost of rehabilitation services, somewhat surprised me, because there are such figures. I am sure that the Vocational Rehabilitation Administration can give them to you. I think, for instance, that the cost of these services is considerable.

One program that I know of in Minneapolis has what we might call a model program, with very comprehensive services for all disabilities, including arthritis. The cost comes to about \$55 a day. I think we ought to think about this a little bit. This is pretty high priced and it may be rather significant.

DR. STILLMAN: During our Work-



shop sessions, all of us physicians were concerning ourselves with the economics of patient care and with the problem of cutting down on costs by rehabilitating people or by getting them out of the hospital quickly and into a cheaper facility. But one person said that we may actually increase the cost of care—very likely increase the cost of care to the whole community. He said, though, that the worth of a program should not be measured by its cost, alone, but by what it accomplishes for the individual. This man was a lawyer who is now directing a Blue Cross Plan, which I thought was very interesting.

DR. LAMONT-HAVERS: Yes, I think the emphasis was on the fact that we cannot keep saying that because of our increased technology we are going to decrease the amount of money that is being spent for health. We are going to have to face the fact that we are going to have to increase the amount of money that is spent for health. But the population will be healthier, yes.

Review of Surgeon General's Workshop

By Cornelius Traeger, M.D.

I was asked to come to this meeting to act as sort of an elder statesman, to review the results of your labors, and to define any gap areas that may have been overlooked. My assignment was to cover all the Workshops. I managed to spend about two hours with each of the Workshops, and I hope I was able to sense the trends that were developed in each of them.

Before I get into details, there are a few ideas that I would like to discuss with you. About one-half century ago the problem of arthritis was simple. If you had arthritis and you had a lot of money, you went to a spa. If you were poor, you went to a clinic where you were given a large box of salicylate tablets and a pint bottle of oil of wintergreen and told to come back in

six months. Since then, we have come a long way. But a wide gap area still exists; and that is the distance between the laboratory and the bedside. I hope that, as a result of this conference, this gap will be narrowed.

You must remember that arthritis begins, and is, in the patient. The disease falls into four definite classes: the ambulatory patient, the patient with walking aids, such as the cane or crutch, the wheelchair patient, and the bedridden patient; and each of these presents a special problem. These cannot be dealt with en masse. In other diseases, such as tuberculosis, diabetes, and incipient glaucoma, it is easy to run mass surveys. The same is true of cancer detection clinics. Early detection in these mass programs has been most successful.

These techniques are not feasible in dealing with chronic arthritis. This is an individual business. Attempts to develop arthritis registries or to devise means of finding susceptibles are fraught with all sorts of difficult and, perhaps, even insurmountable complications and would involve an enormous effort, in terms of personnel, criteria, storage, retrieval of information, etc.

Because of the nature of the disease, the

first place where the patient seeks help is not always the family doctor. It is quite frequently the corner druggist. He is the man to whom the patient goes for a bottle of liniment or a box of pills, or for some remedy that he has heard about on the radio or television. Sometimes he goes to a spa or to a chiropractor. Frequently the first contact the arthritics have with their physician may come after the disease has been present for a few years. The differential diagnosis is not simple. There are 66 different diseases which have as their presenting symptoms pain, swelling, and limitation of motion. They are not all arthritis; and it is in this area of differential diagnosis that the romance of arthritis manifests itself; it is here that the teacher can make his first impact on the student.

I was surprised by the omission of quackery in these deliberations. Quackery does not exist in such diseases as diabetes and pneumonia. Quackery thrives only in an area where the etiology of the disease is unknown and where there is no specific therapy. Quackery thrives in cancer, in many of the neurological diseases, and it certainly thrives in arthritis. One would suppose that quackery could be eliminated by public education. Unfortunately, this

has not been true. "Information, such as we have, is and has been reaching the public for the past ten years in all media. The preparation and formulation of authoritative information in the field of arthritis has been well accomplished. The channels of this information have been well-developed." Public apathy with respect to arthritis simply does not exist. That the public is motivated and is interested in the problem of arthritis is indicated by the fact that this same public spends millions of dollars a year in quackery and nostrums. Why? Simply because the public is discouraged. They see no progress in the scientific field. They are frequently discouraged by the lack of knowledge and the lack of interest when they visit the doctor. The public is confused by the lack of agreement among doctors with respect to the various types of therapy. Unfortunately, we all know this to be true. There is still controversy among rheumatologists with respect to steroids, gold, phenylbutazone, splinting, and even salicylates.

"What is really needed is to arrive, if possible, at some agreement regarding early diagnosis and specific therapy. Many of our concepts of therapy need accurate evaluation. If and when such agreement is

achieved, the next order of business is an educational program."

This program must begin in the clinical years of the medical school. Inspired teachers can, at this level of medical education, stimulate sufficient interest in young medical students to arouse their curiosity and to develop in them a desire to follow through in this most important and fascinating area of medicine. It is from these young students that the Training Grant Programs will best obtain their recruits. The attempt to buy interest in arthritis by subsidizing postgraduate students has not been very successful. "The training of doctors depends on the trainer. The product that is turned out is worth support only if the trainer and the trainee are motivated by a scientific desire that cannot be equated in terms of financial support." You can't buy the man, and you really don't want such a person. The need today is for teachers who are knowledgeable and enthusiastic and who can transfer the excitement of rheumatology to their students.

As I have gone around the country to visit medical schools, I have found that the subject of rheumatic disease gets pretty short shrift. When I was on service at the Hospital for Special Surgery, we would

get two boys—a junior and a resident—from Cornell Medical School to rotate on our service. When they arrived on the Rheumatic Diseases Service, they knew only two things about rheumatoid arthritis: that gold was no good and that phenylbutazone was worse. Most of them were just ticking off the days until they could get off our service. Now, Cornell is a good medical school, and I consider Dr. Freyberg to be one of the best teachers of rheumatology. However, only rarely could we light fires under these boys. The only way we are ever going to get manpower is to develop, in the medical school, teachers at the third-year level with the ability to inspire their students with the romance, the importance, and the challenge that is presented by the rheumatic diseases. At one time, the Training Grant Programs of the National Institute of Arthritis and Metabolic Diseases included 49 Centers. Today, there are only 38; and recruitment remains the big problem. Why?

Almost all of the doctors here present were never recruited, were never subsidized. Nobody proselytized them. They came into this dreary field of rheumatic disease because they wanted to. If there had not been such men as Ralph Pember-

ton, Walter Bauer, and Phil Hench, this meeting might have been delayed 10 years hence. You are not going to make rheumatologists and you are not going to provide personnel by running up and down the highways and byways and bribing young men to come into a Training Grant Program, to come into a Research Grant Program, or to get into this field at all, because they are going to get paid. Unless they are moved, unless they have a feel for this dreary disease, there is no use getting them in the first place. It is very easy for doctors like Mike DeBakey to obtain recruits. Their field of endeavor is spectacular. Their patients are either dead or better in short order. But in the rheumatic diseases, responses to therapy are frequently very slow, and observation and progress reports may extend over several years. Patience, dedication, and genuine interest are necessary in this tedious field.

I remember being approached by one of the pharmaceutical houses to carry out a clinical trial of a new steroid. They asked me how long it would take to get this work done. When I replied, "Five years," they were not much interested, and neither was I. They finally settled for four years. The rheumatic diseases are a dreary business;

and if you are not geared to thinking in these long terms, it is best to stay out of it entirely.

To my mind, there is no greater challenge to the medical student than the one that is presented by these diseases. It is at this point that one can light the spark. The further along a medical student gets in his career, the less interest he is apt to have in the rheumatic diseases. The further along he gets, the greener the pastures look in the fields of cardiology, gastroenterology, etc. Our efforts as senior citizens (I am talking about myself, now) should be to look for the great teachers in the medical schools and to get them to seek out those students whom they think could be inspired to go on to work in rheumatic diseases.

With respect to training, Dr. Whedon indicated that training grants for research include clinical investigation. "Please do not go away with the idea that there is some rigid barbed wire fence around the Training Grant Program of the National Institute of Arthritis and Metabolic Diseases against the investigation of patients as supported by the Training Grant Programs." This is true; but the Training Grant Programs' directors are still loath

to take trainees who are primarily clinically oriented. This is a real gap area that needs further clarification and extension.

Another gap area has to do with the continuity of patient care. What so frequently happens is that a patient comes to a clinic, a history is obtained, and a physical examination is performed. (And I must say that in most of the clinics I have visited the history and physical are very well done.) Then there is the laboratory work and the X-ray studies and, occasionally, in a case of special interest, a clinical conference is held. At this point, all too frequently, the patient is seen on his return visits by another physician who happens to be on duty that day. This is especially true if the patient is referred to either physiotherapy, vocational therapy, psychiatry, etc. The original doctor may not see this patient for a long time. It is my firm belief that it is the doctor's responsibility to followup his patients until the relationship is finished, either when the patient is discharged, when he moves to another locality, or when he succumbs to some intercurrent disease. This is the only way for the physician to learn about the natural history of the disease and the efficacy of his treatment.

It is only by these means that reliable and authoritative knowledge can be presented to the physicians of this country. "The physician is charged with the key role in the management of his patients. All plans for care center about the patient, and his needs are the general responsibility of the physician working with other professional personnel who will meet the needs as they arise."

In this connection, it is important that the physician be thoroughly knowledgeable regarding the availability of all community resources. The physician must make real efforts to find the ancillary resources that are afforded by the community and to use them to their fullest extent.

And now we come to statistics. I do not believe that statistics in arthritis are at all meaningful. We talk glibly about twelve million arthritics. These are really only people who think they have arthritis. A little over three million would be a more realistic figure, since this number includes those who have definite limitation of activity. In any event, statistics are not truly important. If statistics were meaningful at all, the common cold would occupy the sole attention of medical science, and we would have to stop building automobiles and good roads.

The problem of establishing regional centers and satellites was discussed in great detail. The whole problem is fraught with many complications and difficulties, which were adequately discussed. I agree with several of the Workshop Chairmen who suggested that it might be easier and wiser to examine all of the presently existing facilities for the diagnosis and adequate treatment of the arthritic—to evaluate their strengths and their weaknesses. The strong ones could be made stronger, and the weaker and less efficient ones could very easily be brought up to the level of the first-rate clinics. This will do away with committees, coordinators, etc. It will make diagnosis and treatment accessible to all patients in all localities. It will be much cheaper and much more efficient in the long run. “Existing programs need to be supported, strengthened, and coordinated and expanded to geographical areas where

they are lacking. To build along the strengths and bolster the weaknesses of what we have now is important and practical.”

In some of the other discussions, a suggestion was made to attempt to curtail the advertising claims of salicylate derivatives, so commonly heard on radio and television. This, of course, is not our province at all. This is the job of the Federal Trade Commission’s Bureau of Deceptive Practices.

In closing, I want to make one other remark, and that is that we talk a great deal about cooperation between the rheumatologist, and physiatrist, the occupational therapist, the vocational counselor, the social worker, etc. The truth is, however, that we don’t cooperate with them. How often do we discuss a problem case with a social service worker? How often do we discuss problem cases with the psychologist or psychiatrist? How often do

we go to the plaster room and discuss the problems of splinting to correct deformity? The answer: We don’t! But we keep talking about it. We come to meetings and talk about team work and collaboration, but, for the most part, that is all we do about it. I think the only answer is that all ancillary medical and paramedical personnel should make it a point to heckle the clinician.

This conference was called “The Surgeon General’s Workshop On Prevention of Disability from Arthritis.” We have talked about everything else, but I suppose that is only natural. But much more has, and will, come out of this meeting. With clear vision and an intelligent evaluation of the facts and the suggestions that were placed before our Group, I predict great progress in the alleviation of the sufferings of our arthritic fellow citizens.

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