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-- A R T H R I T I S C O N F E R E N C E --

on the

Pilot Arthritis Initiative

January 19 - 20, 1975
Kansas City, Kansas
Muehlebach Hotel

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Conference on the Pilot Arthritis Program
Kansas City, Missouri
January 19-20, 1975

SUMMARY OF THE CONFERENCE

Representatives of 62 pilot arthritis projects being carried out in 29 Regional Medical Programs (RMP's) convened in Kansas City, Missouri, to exchange experiences, and to develop cooperative methods to facilitate optimal program outcomes.* The pilot arthritis program was made possible by a special, one-year earmark of $4,500,000 in the 1974 appropriation for Regional Medical Programs. These funds represent the first significant non-research Federal support to the arthritis disease field. Thus, the program presents unique opportunities, the realization of which are not assured unless the program is continued and documentation is accomplished for projects, and the aggregate program.1/

In recognition of these needs, and the one year period to accomplish program objectives, the Kansas City conferees ratified resolutions relating to the immediate needs of the arthritis program, and longer term requirements for effective arthritis care planning and delivery.

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*Other participants represented: The Arthritis Foundation (AF); American Academy of Orthopaedic Surgeons (AAOS); representatives of Arthritis Foundation Chapters; the Public Accountability Reporting Group (PAR); National Institute of Arthritis Metabolism, and Digestive Diseases (NIAMDD); and the Division of Regional Medical Programs (DRMP), the pilot arthritis grant program sponsoring agency.

1/ In the 1975 supplemental appropriation for the Bureau of Health Planning and Resources Development, HRA, $4,500,000 was authorized to continue the pilot arthritis program.

Immediate needs:

1. The pilot arthritis program must be documented, assessed, and reported to physicians, allied health personnel, and medical and health administrators.

2. Pilot arthritis activities must be kept active until documentation and assessment can be completed.

3. Documentation of the pilot arthritis program should be actively supported by the participating projects and programs.

4. Third-party reimbursement for arthritis services must be developed.

Long term needs:

1. Successful pilot projects should be phased into future medical care systems.

2. Long term goals for delivery of care to patients should be formulated and disseminated.

3. A national clearinghouse is needed to collect and code arthritis patient education material (both printed and audio-visual), and to list alternative modes of treatment and methods of care delivery which have been attempted.

4. A uniform arthritis data collection and reporting system should be implemented.

5. A resolution must be achieved on the legal status of professional allied health and paramedical personnel as care delivery extenders.

The pilot arthritis program has focussed on outreach to make maximum use of existing health resources, and thus bridge the gap between available therapeutic capabilities and the level of arthritis care being provided. The experiences of the pilot arthritis program assume increased importance in prospect of enactment of national health insurance, and the increasing average age level of the U.S. population. The "National Arthritis Act of 1974" (P.L. 93-640) was enacted in January 1975, creates additional pressures on the pilot activities to define methods to facilitate the application of increased arthritis research through coordinated community services.

COMPLETE CONFERENCE REPORT

The conference was convened to bring together decision-making individuals associated with the pilot arthritis programs to share experiences and problems, facilitate mutual assistance, and to explore feasible activities which could be jointly undertaken to enhance program quality, and document the pilot arthritis initiative. The conference Chairman was Dr. Roger D. Mason, Senior Vice President for Health Affairs, Blue Cross/Blue Shield, Omaha, Nebraska.

The conference was organized to address major aspects of the pilot arthritis program during the first day, and to develop in the second day's activities general objectives, and methods to document program outcomes. The discussion perspectives of each days work can be phrased, respectively, "What do we have?", and "Where do we go from here?"

The Conference Charge was delivered by Mr. Matthew Spear, representing the Bureau of Health Planning and Resources Development (BHPRD), Health Resources Administration (HRA). The conferees were reminded that with the imminent phase-out of the Division of Regional Medical Programs, and the 53 RMP's, the task of carrying the pilot arthritis program forward, and to realize its potential fell more fully to them than might otherwise be the case. With RMP resources being absorbed in the newly authorized BHPRD (P.L. 93-641), documentation and assessment of the pilot arthritis program depends on cooperative efforts of arthritis program directors and concerned professional groups. The experiences of the pilot arthritis program are anxiously awaited in view of new information which this program might provide for future investigators, and as preparatory work in connection with the National Arthritis Act of 1974 (P.L. 93-640).

Special Arthritis Program Summaries

The conference began with brief presentations of the activities and problems of five selected pilot arthritis programs.

Dr. F. Richard Convery, University Hospital, San Diego, California, described how a pilot arthritis grant was being employed to establish a coordinated comprehensive arthritis care program. Given excellent incenter resources of research. training , surgery, and rehabilitation, the program will mesh these functions into continuing patient services, including home care. Allied health services, with rheumatologist and orthopedist cooperation, will provide continued contact and followup with the patient in his/her environment to reinforce the special therapeutic requirements with which each patient is variously engaged.

To maintain the comprehensive program, it will be necessary to continue the program beyond the one grant year. A cost evaluation program has been instituted to pinpoint costs, and develop a feasible charge system. The program has attracted a rehabilitation grant permitting complete development of allied health services. A counseling program is functioning with Nurse, Social Worker, Physical Therapist, Occupational Therapist, and Vocational Counseller participation. A home-bound program is developing, and San Diego employers are enthusiastically supporting a return-to-work program. By-products of these coordinated activities include functional review of patients and an assessment of care screen, quantification of input components of treatment and care, clarification of important allied health roles in comprehensive care delivery, and insight into cost-benefit results of the arthritis program.

Dr. Elam C. Toone, Jr., Medical College of Virginia, Richmond, Virginia, related the development in Virginia of a consulting specialist visiting team program operated cooperatively by the Virginia Chapter of the Arthritis Foundation, and the Family Practice Departments of MCV, and the University of Virginia. The program is aimed at providing increased outreach of center arthritis specialities, and improving center-community communication for better patient care. In the organization of these activities, the State was divided into East, and West sectors, and clinic sites were selected to provide optimal coverage of patient populations obtainable with available resources. It is anticipated that over 20 clinic and physician colloquia sites will be visited one or more times during the grant year by arthritis specialists from the two universities, Norfolk, and Northern Virginia centers, where the clinic program is already oversubscribed. The program is well received and actively supported by both physicians and patients.

Ms. Janice Pigg, R.N., B.S.N., Columbia Hospital, Milwaukee, Wisconsin, is the principal investigator in a study to identify and measure the effects of nursing intervention in Rheumatic Disease patients. The study is based on two patient populations in an acute care setting: early rheumatoid arthritis patients, and patients undergoing total hip arthroplasty. A model of quality assurance is being employed to elicit patient outcomes as influenced by nursing practice. A nominal group process is used by two participating groups of staff nurses in writing patient outcome criteria. A statewide nursing advisory committee is reacting to the criteria.

Patient outcomes are written from societal, professional and scientific values. These outcomes are then validated by retrospective nursing audit. The degree of discrepancy between the criteria and current level of nursing practices is assessed. Selection and implementation of an alternative for changing the nursing practice is then made, The result is improvement in nursing practice. This is a continuing process. The on-going review required increases the nurse's knowledge about care of rheumatic disease patients, as well as sensitivity to,

and perception of patient reaction. By-products observed in the project include increased awareness of the nursing role, development of greater expertise in care by the staff nurses, concurrent development of patient education, and broadened understanding of patient concerns and perceptions.

Dr Paul Young, Orthopedic Hospital and Rehabilitation Center, Ashville, North Carolina, reported how careful organziation and coordination of physician and allied health personnel functions in an arthritis clinic permit the clinic physicians to competently handle two times the average patient load reported nationally for physicians. Dr. Young noted that if every menber of the ARA devoted full time clinical rheumatology, only one-half of the known treatment needs would be met. Thus, conventional physician utilization cannot meet the need, and his center has actively developed allied health and private physician support to optimize specialist output.

The hypothesis under which this development was begun some years ago, was: "Carefully designed, meticulously followed, frequently revised programs of drug monitoring permits the use of allied health professionals for the monitoring of potentially lethal drugs with the degree of risk which seems reasonable from several points of view". The process followed by a registered nurse clinician, one of several allied health specialists utilized in the program, was described---from the initial patient visit to care followup by the clinic or a participating family physician. The key to effective operation of the program is maximum routinization of each step for diagnosis and assessment, stabilization and treatment, and followup care.

Allied health personnel services are developed through intensive training in the established techniques and methods that stresses rigorous adherence to protocol, and the use of preprinted prescription and lab test and medication forms which serve both patient record and referral needs. Nearly 70 local physicians participate in the use of these forms.

Based on records compiled over the past 6 years, Dr. Young reported:

1. The number of patients the office can manage has more than doubled.

2. The treated patient death rate is below the published rates for treated and untreated RA.

3. Monitoring has shown that administration of gold, plus cytoxin, plus mexatricate under the rigid protocol is less hazardous than the disease, or treatment with moderate doses of steriods even with physician monitoring.

4. Expanded utilization of allied health specialties has permitted the accumulation of data leading to important modifications in treatment toward less hazardous modes of therapy.

Dr. Balu Athreya, Children's Seashore House, Atlantic City, New Jersey, discussed special needs which arise in the treatment of children with arthritis and outlined the operation of pediatric arthritis activities in the Greater Delaware Valley area (Eastern Pennsylvania and Southern New Jersey). Dr. Athreya estimated that there are approximately 175,000 children with rheumatoid arthritis in this country, but noted that data on this patient group is incomplete because in various surveys of chronic illness in children, arthritis is hidden under the general classification of musculoskeletal problems. Special problems of treating pediatric patients were emphasized. Doctor Athreya noted that children learn by manipulating their environment. While well children can manipulate their environment, handicapped children cannot. This imposes repeated interferences with their learning process. Environment has to be brought to these children, and the environment may also have to be modified to suit their needs. Child patients also experience severe emotional problems and fail to understand the need to continue medication and therapy when they feel well. The demands of therapy for children with arthritis place extraordinary stress on the family, including physical, emotional, social and financial problems.

The principle goals of the pediatric arthritis project in the Greater Delaware Valley area are: 1) family education and followup; 2) education of physicians and allied health personnel; and 3) development of uniform pediatric case records system. Five medical schools in the area are cooperating in the program. Multispecialty backup is provided to physicians who are taking care of children with severe physical or social problems due to arthritis. A Nurse Coordinator is the central figure in the family education and followup program. The nurse is particularly effective in face-to-face sessions with pediatric patients and their parents, and plays a crucial role in home visits, patient records maintenance, school placement and patient referrals. The program has arranged to open the existing three demonstration pediatric arthritis clinics (at Chidlren's Hospital of Philadelphia, Children's Seashore House, and St. Christopher's Hospital for Children). Physicians and physical therapists in the area are encouraged to attend these clinics to learn the special problems of caring for children with arthritis.

Special Speakers

Dr. Gordon R. Engebretson, Coordinator of the Florida RMP, addressed the Sunday, January 19, luncheon group on the development and activities of the Program Accountability and Reporting Group (PAR), an organization of the National Association of Regional Medical Program Coordinators (NARMPC), formed to develop and disseminate national descriptive and evaluative information about RMP programs. Dr. Engebretson represented

PAR in the conference, and since Florida did not receive a pilot arthritis program grant, provided an objective perspective of needs for accountability reporting, and the development of uniform information from among divergent programs supported by the RMP's.

Sunday evening, Mr. David D. Shobe, Director of Government and Community Affairs, Arthritis Foundation, was the dinner speaker. He described and discussed the "National Arthritis Act of 1974" (P.L. 93-640). This law expands the authority of the National Institutes of Health in the arthritis area. Provision is made for the support of arthritis screening, detection, prevention and referral projects, the development of arthritis centers, and education related to arthritis.

At midday, Monday, January 20, Dr. Evelyn V. Hess, University of Cincinnati Medical Center, and Chairperson of the ARA Computer Committee, described the development and purposes of the ARA uniform nomenclature structure, and associated reporting forms. Dr. Hess emphasized the widespread input sought and provided to this program, and underscored the flexibility with which it is hoped the nomenclature and report forms will be received for use in various settings, and continued development. Evaluation of data descriptors is presently underway. The principal use anticipated for common nomenclature is the institution of uniform terms in teaching about arthritis.

Workshops, Sunday, January 19.

Six workshops were conducted, and reported at the Sunday afternoon Plenary session.

Physician Education

Co-Moderators: Russell T. Schultz, M.D.
Charles D. Tourtellotte, M.D.

The workshop identified the following techniques being employed by the arthritis program:

1. PRECEPTORSHIP - Such efforts involve medical students participating in local health care deliveries, as well as physicians returning to medical schools for specialized rheumatoid training.

2. CLINIC PARTICIPATION - Through these techniques, difficult patients are presented to consulting physicians and others in the local community. The medical problem is discussed in some detail and treatment recommendations made.

3. CONSULTATION - Conventional consultation contacts have evolved from outreach efforts.

4. WEEKLY LECTURE SERIES - Some programs have employed regular lecture series on specific problems of the treatment or diagnosis of rheumatic diseases.

5. REGIONAL DAY-LONG SEMINARS - These seminars are usually conducted at a local site by a panel of rheumatologists of the area's medical centers.

6. MEDICAL CENTER SYMPOSIUMS - These are more formalized presentations by outside experts of some renown, and are usually one or two days in duration.

7. SELF OR PROGRAMMED INSTRUCTION - A few programs have developed self-assessment and programed instructions instruments. This technique enables physicians to arrange study within their individual schedules.

8. MEDICAL STUDENTS AND HOUSE STAFF PROGRAMS - There is a conscious attempt in many projects to involve medical students and house staff in the rheumatic disease educational programs.

Problems

The following problems related to physician to physician education were reported by the workshop group:

1. Local physicians are over-worked to the degree that it is seldom possible for them to participate in programs conducted in medical centers.

2. Treatment of the arthritis patient is a team effort; therefore, training should realistically be conducted on a team basis (several team/teaching programs are being conducted with reasonable success).

3. Programs should be planned to meet the individual need of the particular community. Without some degree of tailoring, rapport between the medical center and community may be lost.

4. There is an insufficient number of trained rheumatologists in the medical teaching institutions to meet the demands of an extensive outreach program.

5. Evaluation of the effectiveness of out-reach is difficult.

6. If out-reach programs are so service-oriented that patients begin to circumvent the local health care system, rapport will be lost. Education should be emphasized in out-reach programs rather than patient service.

7. In areas where distances between population centers are great, there appears to be less response to continuing education efforts among local physicians. Distance also creates a teaching resource problem.

8. Not all Medical school faculties enthusiastically participate in out-reach clinics. Many feel their responsibilities lie elsewhere, such as research and institutional instruction.

Evaluation

The workshop discussed evaluation in broad terms. No concensus was achieved on the best ways to evaluate the programs discussed. It was generally agreed that such short term efforts as the one year pilot arthritis initiative could not be evaluated in terms of its effect on patient treatment and physician behavior.

It was suggested that where possible, all programs maintain and compile cost and "students reached" data. With this information, it may be possible at the end of the pilot arthritis program to make judgements concerning the cost of various teaching techniques. This data could be of great value to those responsible for continuation support. It might also be pertinent to an evaluation of the cost of basic medical education in rheumatoid arthritis (as opposed to continuing education).

An assessment of professional education conducted by the A.R.A. and the National Arthritis Foundation was discussed by Dr. Evelyn Hess. Preliminary information indicates a potential shortage of physicians trained in rheumatology, as few house staff and medical students are involved in arhtritis centers. There are also relatively few numbers of post-doctoral fellowships available in rheumatology. Data indicated the existence of less than 2.5 rheumatologists per institution surveyed. (The survey covered 120 teaching and private treatment insitutions).

Final results from this survey may be ready for presentation at the national meeting in June 1975.

Recommendations

Recommendations which relate to the overall task of educating physicians

in the area of rheumatic diseases:

1. Educational programs should be aimed at the needs of the patient and address the physician's problems related to patient needs.

2. The guidelines for funding the arthritis initiative were quite restrictive. Future funding should allow more latitude for program balance between out-reach education, and education of medical students and house staff.

3. A coordinated attempt to gather, assess, and evaluate data on the various education techniques employed in the pilot arthritis program should be implemented. PAR, or a similar organization, should be employed to accumulate the appropriate information for such an analysis.

4. The workshop supports continued funding of the arthritis center approach, and other programs designed for the continuing education of the practicing physician.

Allied Health Education

Co-Moderators: Marjorie D. Becker, Ph.D.
Robert Godfrey, M.D.

Workshop participants summarized their respective arthritis activities, including allied health personnel (AHP) activities. There was general concensus that the potential for AHP education is largely untapped. A massive AHP training program would provide manifold improvements in service delivery through increased support to physicians, and expansion of treatment monitoring and outreach capabilities.

Participants also addressed AHP qualification measures. They noted that AHP certification or licensure should not be so rigid that it precludes using manpower and talent that is presently available. The earliest possible educational interaction between all health occupations should be encouraged. Also, we need to correlate, or to include the AHP contribution within the ARA central health data base.

Recommendations for future AHP educational activities are:

1. Support the Allied Health Professional Section of the Arthritis Foundation.

2. Set up a national meeting of allied health professionals to share their arthritis project outcomes and methodologies. This should

be arranged in conjunction with the National Arthritis Foundation meetings at New Orleans, in June.

3. Request each of the pilot arthritis project directors to assign an AHP coordinator to report specifically on the allied health personnel involvement in their projects. This information should be organized and made available as part of the documented experience of the pilot arthritis initiative.

Anticipated outcomes of greater Allied Health Professional Education:

1. Greater numbers of rheumatic patients will receive services from appropriate levels of health professionals.

2. The total volume of patients serviced will be increased.

3. The level of patient sophistication regarding arthritis therapy will be enhanced and there can be better patient-physician time utilization. This could also help reduce physician resistance to professional education.

Unresolved issues that might provide agenda items for future meetings:

1. Who should be providing AHP education? Should Discipline train Discipline?

2. Who should define criteria for competency, training, and performance?

3. How should we utilize non-physician-Allied Health resources, such as the Arthritis Foundation, and other national and local community health resources, for provision of complementary public education, patient education, and general support services?

The Allied Health Education group strongly recommends that allied health training, recruitment, and research be considered an extremely high priority item when the activities of the National Arthritis Act are being developed.

Patient Education

Co-Moderators: Frank E. Emery, M.D.
William G. Sale, M.D.

The expenses and needs of the education activities of the respective programs vary considerably. Some projects are ahead of others in patient education developments. The problems discussed were:

1. Dissemination of educational information; who should be responsible for this in local arthritis centers.

2. The need for educational material which is responsive to the geographical, social, and economic needs of various patient groups.

3. The need for a method to evaluate the effect of patient education.

4. The need for providers for carefully developed information to help them answer patient questions, and discuss patient problems.

5. The need for the central source to accumulate and disseminate tested arthritis patient educational materials.

The Arthritis Foundation is urged to compile and list, through its Chapters and affiliated organizations, all of the arthritis patient education materials now being used.

Demographic Factors

CO-Moderators: O. Lynn Deniston
Ms. E.L. Hebbeler

The workshop participants developed a definition of "demographic factors" to help organize data which define patient and/or provider characteristics, and a broader data set which relates to programmatic goals. It was agreed that classical data is needed to augment programmatic information, and the combined results are required for effective planning.

The workshop developed a set of demographic classifications, and potential data sources.

I. Patient Data

Age
Sex
Income
Occupation
Health Insurance
Weight
Family History
 -family rheumatoid
 -personal history
Smoking Patterns
Level of Education
Race
Urban-Rural
Language Spoken
Living Arrangement
Functional Capacity
 -diagnosis rheumatoid
 -diagnosis other
Other Health Care
 -traditional
 -nontraditional
Mobility
Transportation

II. Population Data

What is normally available through the use of census data and any related national or local resources. The objective is to develop a description

of the whole community with scope and detail similar to that indicated above for patients.

III. Provider Data: (both physician and AHP)

Practice Arrangements
Professional Profile
-age
-training-specialty
-place of education
-place of residency
-involvement of allied health professionals

Physicians' Referral Patterns
-frequency
-reason
-other medical services
-social services
-other health services
Patient Management

IV. Institutional Data

Hospitals
LTC
Home Health Services

Social Services
Vocational Services
Mental Health Services

V. Community Data

No. of Physician per Population Ratio
Medical Service Area
Population Density
Volunteerism

In planning an arthritis program, the data suggested in items I thru V should be explored to the extent available. When delivering care, it is suggested that all of the previously identified patient data would be pertinent to comprehensive patient care. When conducting an educational program directed at providers, it is suggested that the previously mentioned data under the listing of "Provider Data" and Community", be utilized.

Potential Sources of Data

I. Population Data

Bureau of Census
Bureau of Labor

II. Patient Data

For potential patient forecasting
-hospital discharge data (UHDA)
-ambulatory care data

-Public Health Department
-314 b Agencies
-National Center for Health Statistics
-National Health Survey
-Experimental Medical Care Review Organization
-Experimental Health Services Delivery Systems

For patients being served:

It is suggested that the best source of information is the patient himself/herself.

III. Provider Data

American Hospital Guide Issue
AMA Directory
State and Local Directories
State Licenser Boards
PSRO's

If the above prove unsatisfactory, or inadequate, it may be desirable to interview providers directly. It is recommended that this be done in only selective situations, and as a last recourse.

IV. Institutions' Data

Medical Care Standards, State Agencies
State Institutional Licensing Regulatory Authorities

V. Community Data

Center for National Health Statistics

It is suggested that local volunteer resources be explored.

Long Term Program Goals

In the light of the scope of the current pilot arthritis projects, and recently enacted legislation, it is suggested that collective action be taken in the following three areas:

1. An appropriate mechanism be devised to facilitate uniform data collection from the 29 funded pilot arthritis programs.

2. The present arthritis programs, coupled with new legislation for new arthritis program advances, intensify the need for collective evaluation of all the funded arthritis projects through a central agent.

3. The PAR could be a resource for centrally collecting and disseminating project data. Further, this activity appears to be appropriate for PAR, and consistent with the responsibilities delegated RMP's to evaluate operational projects. Recognizing the constraints imposed by the limited pilot arthritis program funding, projects should accumulate demographic data from the start of the different projects, and there should be 9-month, 12-month, or similar periodic reporting. In view of new arthritis and health planning and resources development legislation, it is important to know how well projects are meeting their stated objectives, and their outcomes. This information should be made available to various HEW agencies, and to the arthritis program directors.

Arthritis Services

Co-Moderators: Gene V. Ball, M.D.
John L. Magness, M.D.

In reviewing the activities of the participants' projects, there was general concensus that an important part of the arthritis service program was decentralization of present services from medical centers and medical clinics out into the respective communities. Three major types of arthritis services are variously being developed through the projects:

a. An area of physical treatment
b. An area of social and emotional treatment
c. An area of economic, vocational and educational treatment

A discussion of what constitutes comprehensive arthritis service reflected considerable variablility in physician's use of community resources. Participants addressed the use of volunteer organizations, charitable organizations (including the Arthritis Foundation), available community resources such as the Public Health nurse, and fixed or mobile evaluation and follow-up teams in order to provide service for the arthritic. The employment of screening programs operated by nurses in outlying communities is a way to extend out-reach. Care should be exercised, however, to prevent the establishment of a duplicative referral system through such programs.

Broad experience is being obtained in the staffing and use of evaluation and followup teams. Two general types of teams were described: 1) Teams using specialized physicians (orthopedists, rheumotologists, physiatrics, and pediatricians), with allied health personnel fulfilling a constructive role; and, 2) teams comprised primarily of allied health personnel variously combining the skills of nurses, arthritis specialists, physical therapists, occupational therapists, social service workers, and psychologist and nutrition specialists. The teams varied in thrust from those that are designed primarily to act as demonstration, or teaching teams, to those designed to engage in diagnosis and treatment. Both types can undertake the development of community resources.

It was emphasized that there is continued need for centralized resource centers with sophisticated seralogic laboratory capabilities. Such centers provide the resource and research data required to handle complicated illness, and particularly to back up specialized clinics for juvenile rheumatoid arthritics, geriatric, and lupus problems.

A discussion was held on the role of Allied Health personnel in the arthritis treatment and service programs. Considerable philosophical differences exist regarding appropriate responsibilities of nurse practioners, and allied health personnel. Some concensus was reached that there is need for a nurse arthritis specialist to be involved in an evaluation, data collection and treatment situation under the supervision of the physician in charge of the care of the arthritic.

Service Deployment

Co-Moderators: Raymond E.H. Partridge, M.D.
Donald Riggin

Question was raised as to how the majority of existing arthritis services are provided to arthritis patients. It is through the private physician, particularly local medical practitioners. Discussion ensued regarding the degree to which physicians know what is available to arthritis patients in the area. While services may be available that the physician is unaware of, it is also apparent that many available services are competitive rather than cooperative. There is a wide need for directories of resources.

Unresolved questions included: whose responsibility it is to oversee directory development; and ultimately, who should organize the deployed arthritis services that are available?

Circumstances that effectively inhibit service deployment and use were discussed. Some of these are: 1) The conservative nature of physicians;

2) fear that patients referred to other clinics or facilities will be lost; 3) poor education of physicians regarding the services that other arthritis resources can offer; and, 4) suspicion about government-financed services. Other inhibiting factors of service deployment and utilization from the patient's perspective are principally financial, particularly the patient's ability to pay. It was felt that there should be greater willingness by insurance carriers to pay out-patient fees to support increased access to care, and reduced cost of care which can be realized through out-patient services.

It was noted that with National Health Insurance being discussed in Congress, increased publicity should be directed to patient financial problems, and opportunities for financing improved care in the arthritis field. All areas of concern for arthritis patients should be addressed. Activities of the RMP's are producing results in changing attitudes of local physicians and patients toward referrals. It was felt by physicians representing rural areas that a marked impact is being made, and that physicians are becoming much more familiar with arthritis problems, and handling them with greater ease. There is a parallel improvement in utilization of services. The need for early diagnosis and the development of diagnostic centers was emphasized, utilizing peripheral facilities for continuation of the program. There is a great need for physician and patient education as to what services can be provided. Should one concentrate on quality, or quantity of care? It was generally felt that the first priority is to increase the available access to adult medical care by arthritis patients.

Panel Discussion

Program Evaluation and Assessment

Panelists: Gordon R. Engebretson, Ph.D. Moderator
O. Lynn Deniston, University of Michigan
Evelyn V. Hess, M.D., University of Cincinnati Medical Center
Carl W. Schartz, PIMA Health Systems

Mr. Schwartz described a health information system developed by PIMA Health Systems, an experimental health service delivery program funded by the Bureau of Health Services Research to provide health activities evaluations. A periodic reporting system has been instituted for the pilot arthritis program established in southern Arizona to provide evaluative data related to the six objectives of the program. Mr Schwartz discussed aspects of the evaluation program which will permit data accumulation and assessment, as well as appropriate project modification with regard to the quantity, quality, and cost effectiveness of activities.

It is anticipated that development of extensive sociologic information, and patient and clinical services assessment criteria will provide a method to comparatively assess arthritis clinics in different geographic, and sociologic settings.

Mr. Deniston adapted Einstein's relativity formula to highlight important aspects of program evaluation, characterizing evaluation as a "bunch of relativities". An important relativity often overlooked, and leading to doubts of the validity of findings, is causality of results. Health program evaluation must encompass E=M+C+C (Evaluation=Measure + comparison + causality). Evaluators may tend to report, for instance, that a before-after change in a patient group is the result of what was done for them in a treatment sequence, while comparison with a similar, untreated group may reveal similar changes. Thus, the cause of change is not that which was projected, and the service requires further consideration. Causality must be taken carefully into account in effective evaluation. Two principal ways are: 1) development, or location of a control, or comparison situation or group, and 2) a time-based approach through which status (high or low, good or bad) is periodically recorded over time. In either circumstance, a "whole group" perspective must be maintained to prevent attribution of artificial characteristics to the phenomenon being assessed. Mr. Deniston noted that when neither the comparison nor time-based approaches can be employed, assessment must be carefully designed with regard to the environment's causal forces.

Dr. Hess stressed that the Conference charge regarding evaluation is to develop methods and systems, more than to apply them in the short pilot arthritis program time remaining. In view of new arthritis legislation, this opportunity occurs at a fortuitous time, Dr. Hess advocated simplicity in program evaluation, cautioning against a tendency to delve too minutely for answers to unasked questions, or to attempt to observe what purpose, should be defined before the evaluation process or system is initiated. Rarely does everything need to be evaluated, and the program will be adversely effected if evaluation objectives are given priority over substantive program objectives.

Dr. Hess also reiterated the need for attention to outcome causality. Many variables exist which create problems in evaluation. Investigators may be able to control some, but value measures must be determined which are clearly functions of controllable variables. In this respect, the "pieces of paper" used in data accumulation, and the manner in which they are used may well be causal factors. themselves, on the outcome.

Dr. Engebretson addressed broad pilot arthritis program assessment needs. He suggested that the framework of the assessment should encompass disease

intervention activities, project organization, management, and supporting services. This would provide a program mosaic against which the allocation of resources, expenditures of effort, and program accomplishments could be assessed. The acquisition and organization of such information would permit program assessments by an expert group, such as the American Rheumatism Association, with respect to feasible activities, and long-term goals of national arthritis programs.

The broad assessment questions of the pilot arthritis program require identification of the:

1. objectives of the programs,
2. activities of the programs, and
3. measurement criteria related to the objectives.

Analyses should be performed on program planning, organization, direction, monitoring, and control. The effects of linkages between official, and voluntary groups should be documented, as well as performance standards and outcome criteria of activities. The existence, and effectiveness of reporting systems should be known as well as the manpower and other effects of laws, regulations, and licensure or certification requirements. The availability of sufficient numbers and types of health manpower, and provisions for their education and training must be considered, and the effects of disease intervention activities initiated under the arthritis program, or with which activities are coordinated.

Resolutions and Recommendations of the Arthritis Conference

Identification of activities to foster program outcome reporting was the central consideration of the Workshops, and Workshop Reports on the final conference day. All of the recommendations presented were approved after modification in the final Plenary session. The summary reports of these Workshops, and the conference-approved recommendations and resolutions are as follows.

Program Documentation

Co-Moderators: F. Richard Convery, M.D.
Carl Hl. Eisenbeis, M.D.

The workshop participants agreed on four (4) aspects of pilot arthritis program documentation, and evaluation.

1. Documentation should be according to objectives of the programs.
2. Effort made under the program is probably most easily documented.

3. We should not expect to measure outcome other than by numbers served.
4. Documentation at the end of one year is of value primarily with reference to future planning.

The processes identified as being measurable by numbers and amendable to cost analysis were:

1. Numbers of training persons and sessions.
2 Numbers of personnel trained.
3. Numbers of centers established.
4. Numbers of patients treated.

It was emphasized that most programs are designed to expand services by education and outreach. Therefore, documentation should be numerative, and not intended to provide conclusions regarding training effectiveness and quality of care.

Documentation should be organized so that the following elements can be identified:

1. Effort
2. Performance
3. Adequacy
4. Efficiency
5. Process

Recommendations on Program Documentation

Conference Action

Approved 1. RMP should provide a common data collecting system for uniform documentation.

Approved 2. Documentation should be reviewed and evaluated by sub-units of RMP, AF, and AAOS.

Approved 3. Summaries when completed, should be made available to all interested parties.

Special Report Opportunities

Co-Moderators: Ivan F. Duff, M.D.
John L. Kline

We note that the stress on reporting the achievements of the arthritis initiative is to place emphasis on primary patient care---NOW. That a

majority of the projects are doing this is reflected in their activity reports. This concept of responding to the needs of patients -- of doing something for them now -- should, we feel, be protected and fostered in the realization of the National Arthritis Act which in its language places stress upon research.

In all of the projects, education is either a major or a minor outcome. Education should not be aimed at any one group, but should enhance the activities of all concerned; i.e. physicians, allied health professionals, patients, their families, and the public. Because of the multiplicity of efforts being made to design good educational materials, we urge that a national clearinghouse be established. We strongly encourage the Arthritis Foundation to respond to this critical need. Coordinated development is needed for the creation of educational materials designed in response to documented patient, physician and allied health professional requirements. The education clearinghouse should actively seek out and maintain working relationships with other organizations already dealing in the development of educational materials.

In this workshop, eight of the 12 projects represented are actively collecting data. We encourage these activities in the light of the establishment of a national arthritis data base. A central repository accessible and responsive to the needs of the field must be established to collect and organize data generated in the arthritis initiative. It is recommended, because of the present lack of uniformity in reporting, that each project immediately remit copies of their data collecting instruments to Dr. William Campbell, who is associated with the Tennessee Regional Medical Program arthritis project. (William Campbell, M.D., Fort Sanders Professional Building, Suite 605, Knoxville, Tennessee 37916). He will only assemble and disseminate the instruments as requested by the project people. It is also recommended that central collection and dissemination of uniform program information be undertaken by the Public Accountability and Reporting Group (PAR), or another appropriate entity, but under specifications established by a professional arthritis entity, such as the ARA Computer Committee.

It is recommended for the future that high priority be assigned to evaluation of: (1) long term efficacy of comprehensive (optimal) arthritis management versus episodic care, i.e. the usual type of clinical care; and (2) the effectiveness of the nurse practitioner complementation to the physician. A cooperative report based upon the contributions of everyone involved in the training of nurse practitioners in arthritis is desirable.

Third party reimbursement of allied health professionals should be explored in a cooperative report which identify opportunities to include allied health professional care services as a reimbursable item.

It is recommended that linkages be established between the various levels of care providers; this will optimize their utilization, and refute the complaint that what we have to offer is not being maximally utilized.

Among special studies that should be reported we include: (1) Arthritis in industry; (2) Alabama's Medical Information Service by Telephone, i.e., the MIST program modified to the needs of practitioners with arthritis patient problems; and (3) the program of the Western Pennsylvania RMP, which defines deficiencies in knowledge, appropriately gears up their educational efforts, and subsequently provides follow-up evaluation of their efforts. Other on-going studies should also be reported.

Throughout this conference, very little has been said about the methods and problems of outreach into the community. We wish to reaffirm that this is what the arthritis program is all about. A cooperative report based upon our individual experiences is needed to record the methologies variously used, and the solutions to the problems which we have encountered.

In conclusion, we are agreed that experiences from this initiative should form a basis for activities to be sponsored through the National Arthritis Act.

Recommendations on Special Report Opportunities

Conference Action

Approved 1. The establishment of a national clearinghouse for educational materials, efforts and methodologies be directed to the Division of Long Term Care of the Health Resources Administration, PHS, and the Arthritis Foundation. These offices should actively seek out and maintain contact with other pertinent organizations dealing in the development of education materials.

Approved 2. Because of lack of uniformity in data collection, each project should immediately remit copies of its data collecting instruments to Dr. William Campbell, Bioengineering Medical Program, Department of Engineering, Science and Mechanics, University of Tennessee, Knoxville.

Approved 3. The central collection and dispersion of data be undertaken by the Public Accountability and Reporting Group (PAR) or another appropriate entity, under the specifications and guidance of the ARA Computer Committee.

Approved 4. Evenually, high priority must be assigned to definitions of (1) the long term effectiveness of different modes of health service delivery employed in the important types of arthritis, and (2) the effectiveness of the nurse practitioner and the physician. A cooperative report based upon the activities of everyone involved in the training of nurse practitioners is desirable.

Approved 5. Third party reimbursement for arthritis services should be explored in a cooperative effort.

Approved 6. A cooperative report should be developed, reflecting outreach experiences in the arthritis project.

In conclusion, we are agreed that experience from this initiative should form a basis for activities to be sponsored, in the future, by the National Arthritis Act.

Care Delivery Initiatives

Co-Moderators: Roy L. Cleere, M.D.
C.H. Wilson, Jr., M.D.

The workshop explored the prevailing pattern of arthritis care delivery in the past which has been a primary care physician, one-on-one delivery system. A number of weaknesses of this system were pointed out:

1. A lack of proper utilization of allied health disciplines in the care of the patient with arthritis.
2. When all care and patient education is provided solely through the physician, medical capabilities may be inordinately diverted into services which frequently can be provided more effectively by health professional disciplines.
3. Prevailing practices have inhibited full functioning of some of the allied health disciplines because of the ambiguity of legal systems based on this with regard to legal liability.
4. Frequently, the physician is innundated in delivering primary care so that he is unable to participate in continuing education activities.

Only one strength of this system was pointed out, and that was the very significant rapport developed between patient and primary care physician. It was felt that this could be transferred and shared with other members of the health team without decreasing any effectiveness of care.

In exploring the impact of the pilot arthritis program on the health system, a number of project discriptions were explored and discussed, varying from a traveling clinic delivering care over large areas and for screening and diagnostic processes, to a more stable, permanent clinic development program in community hospitals. It is felt that all of these are significant demonstration projects fitting the demographic situations for which they were designed. The major effect is in the demonstration of the team approach to the delivery of services, as well as educational opportunities for those involved in the care of the arthritic patient.

It is felt that these projects are significant, and that they need to be continued for a longer period of time to effect proper evaluation of their impact, as well as for continued delivery of primary health services. If there is a gap period in which funds are lost before proper evaluation can occur, the impact of these systems will be lost. Therefore, every effort should be made to continue interim support of these projects.

Recommendations on Care Delivery Initiatives

Conference Action

Approved 1. As many as possible of the care delivery projects of the arthritis program be continued beyond the present grant period by asking that immediate funding be made available, effective July 1, 1975 to keep these programs going during the transitional phase after the RMP has terminated.

Approved 2. The arthritis program initiatives should be extended, where there is a promise of learning from them, until such time as this learning can be demonstrated. Potential sources are unexpended project funds, other RMP resources, industries, etc. Another source of continuing funds may exist through extending contract benefits with health insurance organizations such as Blue Cross and Blue Shield.

Approved 3. That this conference request the National Arthritis Act Commission to consider recommending funding for care delivery systems that are not primarily related to large research institutions.

Approved 4. That personnel in the arthritis programs contact the Governors in their states for input into the composition of the health councils. That contact with

the councils then be continued to seek funding through the National Health Planning and Resources Development Act.

Program Continuity

Co-Moderators: Ephraim P. Engleman, M.D.
David D. Shobe

Participants developed and analyzed a list of the variety of funds being utilized by the arthritis prjects, including arthritis chapter funds, some private resources, certain support from the National Institutes of Health, as well as fees for services. In the latter category it was indicated that in most cases, these are currently being paid by patients, but that project directors have applied, or are applying, for reimbursement of these fees by Medicare, Medicaid, or other third party payers.

It is of interest that in none of the programs represented in this Workshop has there been support from anv other voluntary health agency, or from any State sources. It was reported that the Federal Government is now directing a variety of mechanisms that pay nearly one-half of all medical care, but third party payers are responsible for another major part, and the amount and type of payment is negotiated. When the services of allied health personnel are reimbursed, payment is usually limited to in-patient services, and at rates which are often the same as those paid to physicians. In some states, however, rates have been reduced by law to a lower fee schedule. Patient educations services are also reimbursed on an in-patient basis, when paid. The arthritis programs should assert every effort to preserve, if not increase, presently available funds.

The question of future funding revolved around four central issues.

1. The possibility of additional RMP funds which may be available in the regional programs. While there is a Congressional continuing resolution which provides up to 78 million dollars during fiscal 1975, it is limited for use connected with the transitional activities of Health Planning and Resource Development programs.

2. The new Health Planning Resources Development Act (BHPRD) was reviewed. It was pointed out that project funds were unlikely to be available until late 1976 under this authority. Health Service Agencies authorized under the HPRD will not be identified with educational institutions, and this is an important contrast with the centers authorized under the National Arthritis Act.

3. The National Arthritis Act was also discussed, particularly the section dealing with screening and detection. It was pointed out that if funds are made available to implement this section, it is possible that they could be applied to some of the current arthritis activities. The research contemplated in the National Arthritis Act centers will encompass clinical research, as distinct from bench research. There is no prohibition against outreach from the centers.

4. The fourth area of future funding discussed was the possibility of approaching Governors and State legislators to authorize continuance of specific programs, the loss of which would terminate care in the area.

It was agreed that all Arthritis Foundation Chapters in areas where pilot arthritis programs are currently in existence insure publicity for these programs, and where possible, try to develop continuation funding for those projects for which public funding will no longer be available.

Recommendation on Program Continuity

Conference Action

Approved

1. Pilot arthritis programs should, wherever possible, be phased into other supporting mechanisms, including:
   a) fees for service, and third-party payments,
   b) private support
   c) transitional funds (P.L. 93-641), and clinical research outreach, and screening funds, as appropriate (P.L. 93-640).
   d) Arthritis Chapter support.