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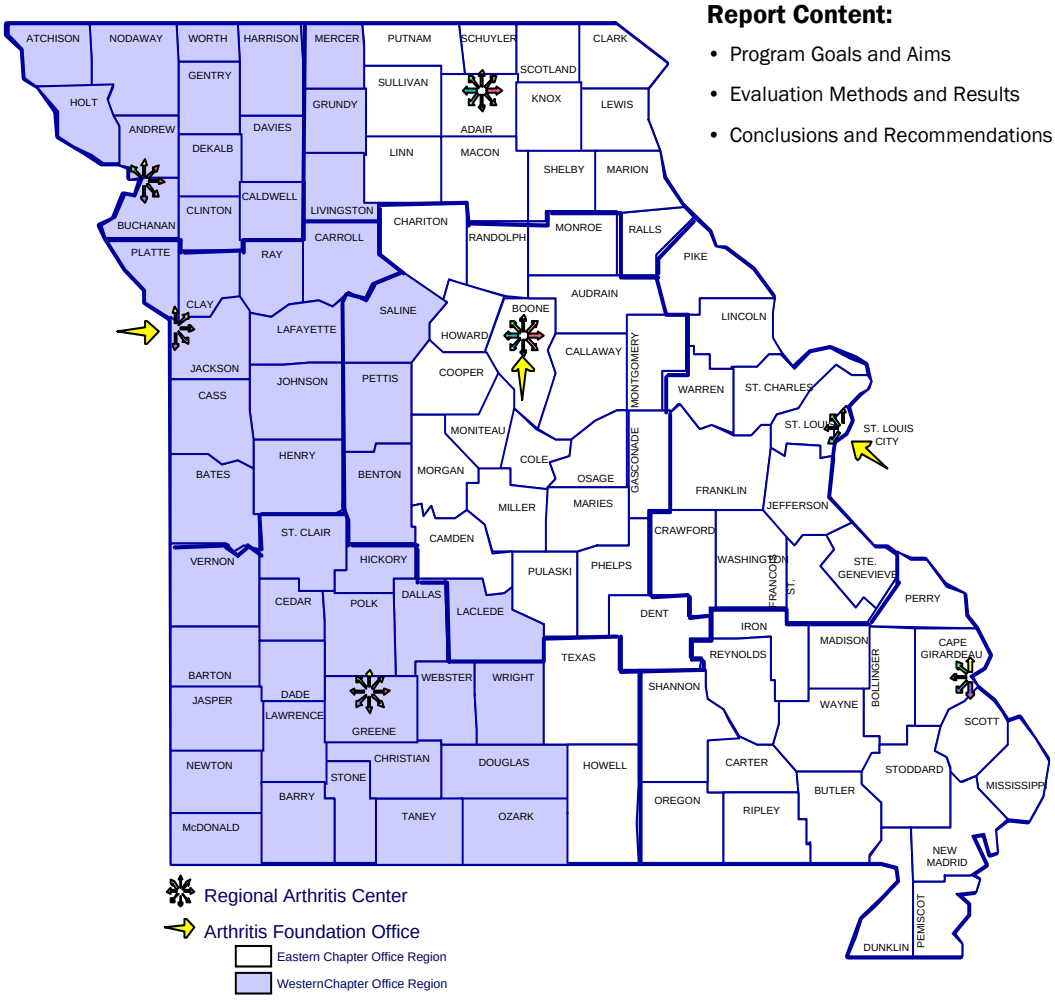
Missouri Department of Health & Senior Services

A Qualitative and Quantitative Evaluation
1985-2000

Evaluation of the Missouri Arthritis & Osteoporosis Program

Report Content:

- Program Goals and Aims
- Evaluation Methods and Results
- Conclusions and Recommendations



Arthritis and Osteoporosis
Missouri Department of Health & Senior Services
Chronic Disease Control

Evaluation of the Missouri Arthritis & Osteoporosis Program

A Qualitative and Quantitative Evaluation
1985-2000
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Foreword

Arthritis encompasses more than 100 diseases and conditions that affect joints, the surrounding tissues, and other connective tissues. It affects nearly one of every three Americans, making it one of the most common diseases in the United States and the leading cause of disability. Arthritis has become one of this nation's most pressing public health problems.

The MAOP was established in 1984 in response to the Missouri Task Force initiatives on arthritis. In 1980, the Task Force presented a three-volume report to the Governor, the Legislature, and the State Board of Health detailing the problem of arthritis, a summary of testimony at public hearings and recommendations. Results of these reports, testimony, and efforts eventually resulted in the passage of legislation creating Missouri's arthritis program. Long range goals outlined in the plan, "to make optimal diagnostic, treatment and rehabilitation services available and accessible to all persons afflicted with arthritis and related musculoskeletal diseases in Missouri" are the foundation of its mission to promote optimal health and quality of life for all Missourians affected by arthritis, rheumatic diseases and related musculoskeletal conditions. These aims are met through a multidisciplinary approach with emphasis on early diagnosis and treatment and self-management to maximize effective benefits to persons with arthritis.

As outlined in the legislation that established MAOP, a network of Regional Arthritis Centers (RACs) were established in 1985 and continue to be an integral component of the program, providing services for people with arthritis. The RACs are located at hosting institutions, in seven regions of the state, and provide self-management programs, professional education programs, and public awareness activities. Additionally, as proposed in the legislation, the Missouri Arthritis Advisory Board was created and continues to be an active and important component of the Missouri's arthritis program.

The Centers for Disease Control and Prevention along with the Arthritis Foundation and the Association of Territorial and Health Officers developed the National Arthritis Action Plan (http://www.cdc.gov/nccdphp/pdf/naap.pdf).

Executive Summary

Shortly after the release of the National Arthritis Action Plan, CDC began working with the Arthritis Foundation and other partners to implement the Plan and support start-up activities. CDC funded 28 establishment states and five (5) core states, including Missouri. Core states had to demonstrate capacity to address arthritis prior to being funded. Missouri Arthritis & Osteoporosis Program (MAOP) has a long history of addressing the needs of Missourians with arthritis through collaboration, leadership, advocacy, and program implementation. As part of the response to CDC funding, the MAOP determined it necessary to evaluate its previous fifteen-year effort. This evaluation was conducted to assure that the program had accomplished aims established at its creation and to help guide future evaluation efforts.

MAOP contracted with the St. Louis University School of Public Health to conduct this initial evaluation. This report reviews the findings from that evaluation and includes:

- Initial steps taken to establish the MAOP,
- Review of MAOP's activities,
- Examination of specific information and service needs of individuals served by the Regional Arthritis Centers,
- Specific needs and concerns of the RAC coordinators and program administration,
- Brief review of program report data and program costs, and
- Summary of findings.

MAOP through these partnerships has successfully provided prompt and effective application of available knowledge for treatment of persons with arthritis and related conditions to the community and health care professions. Focus groups of program participants strongly indicate that the programs offered through the RACs are very beneficial. All people who attended the focus groups found they had definitely benefited from the programs they participated in and significantly improved their overall quality of life.

Resources to effectively promote awareness of the RACs among healthcare providers, individuals with arthritis, and the public were identified as one of the program's greatest challenges. Ability to document program penetration and evaluative measures of health outcomes will help guide future efforts to help determine the continued success of MAOP.

MAOP has met aims outlined at the onset of the program by the Task Force, including the establishment of a Regional Arthritis Center system; the establishment of a Missouri Arthritis Advisory Board; and providing physical activity, self-management, and educational forums for people with arthritis and their families; as well as remaining current on arthritis related issues including treatment and self-management techniques.

The organization of the RACs and the funding streams appears to be an optimal way to achieve the aims of the arthritis program. However, further evaluation is needed to better understand implementation, funding, methods of implementation that can be improved or enhanced, and if funding is adequate to truly reach the target population.

Awareness of the RACs varies, though overall, this is a weak area of the program. Many individuals do not realize that the services they receive are from the RAC. Some confuse the RAC with the Arthritis Foundation.

Focus group members were very satisfied with the information and services they were receiving including materials and assistance with managing their arthritis. One barrier that was prevalent when discussing the aquatics programs was water and room temperature; often the temperatures were too cold.

Executive Summary

Several issues of the RAC System still need to be evaluated. Issues include: Is the RAC system effectively and efficiently providing programs and services within their respective regions? What are common approaches, standards, and components of each RAC office? Are there additional barriers to program implementation and expansion? Is the system working well? What can be improved or enhanced? What needs to change? What is the penetration of the program? Is funding adequate for the system to meet the needs of Missourians with arthritis? Has funding had an impact on the programs over the years? Is the program cost effective? To comprehensively assess the program, additional focus groups, interviews, evaluations, and statewide surveys may need to be conducted to completely evaluate the impact and outcome of the program and assess if the program is achieving its mission "to promote optimal quality of life for all Missourians affected by arthritis or other rheumatic conditions through early interventions, education, service, and collaboration".

". . . when she came to our Church. She wanted to see if some ladies were interested in this class. I got a group started . . . . We meet once a week. I really get a lot of good out of the exercise. [sic] I have arthritis. . . ."

— Participant, NE Missouri

" . . . . I can't imagine going back to isolation . . . ."

"I think the quality of life has improved mentally."

I think improvement in sociable [sic], flexibility, and mobile [sic]."

". . . Notifying the general public as to what all is available, it can be a very costly thing."

— Participants, SE Missouri

Program Purpose & Key Evaluation Questions

Program and Purpose

Arthritis is one of the most prevalent of chronic health problems and the nations leading cause of disability. Although often perceived as a disease of the elderly, arthritis affects people of all ages and all socioeconomic groups.

Arthritis is an umbrella term. There are over 100 joint and connective tissue diseases related to arthritis. Most forms of arthritis affect areas in or around joints. The disease can also affect other parts of the body, and cause pain, aching, stiffness and sometimes swelling. Common types of arthritis include: osteoarthritis, rheumatoid arthritis, gout, systemic lupus erythematosus (SLE), spondylarthropathies, juvenile arthritis and fibromyalgia. All of these conditions can cause disability and limit peoples ability to engage in the activities of daily living.

There is no cure for most types of arthritis, but the effects of the disease can be reduced considerably. Effective interventions to prevent arthritis and its complications include early diagnosis and appropriate medical treatment (pharmacological, physical and occupational therapy, and joint replacement), self-management (weight control, physical activity, and treatment compliance) and education. To maximize these benefits, however, people with joint problems need to understand their condition and actively participate in their own arthritis management.

In Missouri, arthritis or chronic joint symptoms affect 1.5 million persons or 38.6% of Missourians 18 and over in 1999. Despite the potential seriousness of this disease, many people haven't seen a doctor for their arthritis; many do not know the type of arthritis they have.

To promote optimal health and quality of life for all Missourians affected by arthritis, rheumatic diseases and related musculoskeletal conditions, the Missouri Arthritis Program was established in 1984 and has been serving the needs of people with arthritis since. There are seven Regional Arthritis Centers (RACs) around the state and each center serves from 10 to 24 counties. These RACs serve as local resources for arthritis information, medical referrals, and arthritis programs and services. These services address and support key issues related to arthritis through self-management programs, professional education programs, public awareness, health fairs, individual counseling, and seminars. These RACs are all located within hosting institutions that have the ability to provide comprehensive health care for individuals with arthritis and other rheumatic conditions.

Key Questions

In 2000, The Missouri Arthritis Program contracted with Saint Louis University, School of Public Health to conduct a systematic and critical review of the structure, process, and implementation of the program. Some of the key questions addressed in the evaluation process are:

- What are the aims of the Missouri Arthritis Program? Have these aims been achieved?
- Is the organization of the RACs and funding the RACs a good way to achieve the aims of the Missouri Arthritis Program?
- Are people aware of the RACs and the services they provide?
- As different people access the RACs, are they getting what they need in terms of:
    - Appropriate materials
    - RAC accessibility
    - Helping to manage their arthritis
    - Barriers to receiving care
- What is the penetration of the program?
- What kinds of data are being collected? How can data collection be improved?
- How has the funding affected the program over the years?

This evaluation report attempts to answer all these questions and make recommendations for the future.

1 Ankeney ME, Vradenburg JA, Shetty G. Missouri Arthritis Report 2001

Program Description

In September 1976, the Missouri Task Force on Arthritis was organized to conduct an arthritis needs assessment program in Missouri. This task force was comprised of physicians, allied health professionals, representatives from the Arthritis Foundation, a state senator, an attorney, patients with arthritis, and members of the public. The task force developed work groups for health care, professional education, manpower, public education, research and public affairs and divided the State of Missouri into seven regions to conduct a needs assessment. These regions were: St. Louis metropolitan, Southeast, Northeast, Northwest, Central, Southwest, and Kansas City metropolitan. Public hearings and site visits were conducted at each of these regions with the help of volunteers. This led to the development of a three-volume report released in 1980 regarding the status and availability of health services for people with rheumatic disease.

In January 1980, the three-volume Report of the Missouri Task Force on Arthritis was submitted to the Governor, the Legislature, and the State Board of Health.

Three-Volume Report of the Task Force

Volume I – The Plan: This volume detailed the problem of arthritis in Missouri and the costs attributable to arthritis. It summarized the testimony at public hearings (Volume II) and made recommendations. The plan also outlined the long-range goal of the Missouri Arthritis Program, which was "to make optimal diagnostic, treatment and rehabilitation services available and accessible to all persons afflicted with arthritis and related musculoskeletal diseases in Missouri". This plan also analyzed existing services and support programs (Volume III) relating to arthritis in Missouri and made twelve recommendations for a State Arthritis Plan. The first recommendation was to establish a Network of RACs around the State of Missouri. This recommendation states, "The State should establish a Network of RACs designed to demonstrate and stimulate the prompt and effective application of available knowledge for the treatment of patients with arthritis and related musculoskeletal disorders, and to develop new knowledge essential for the control of these disorders". Some of the proposed activities of the RACs included:

- Educational programs for patients with arthritis and the public
- Continuing education for various health professionals
- Community education for all areas served by the RACs
- Assessing availability and access to health services in each region
- Assuring optimal professional education for arthritis specialists

The Task Force also recommended a Missouri Arthritis Advisory Board be formed and a position created for a state arthritis program coordinator.

Volume II – The Public Hearings: The second volume of the report is the testimony of eight public hearings held in all regions of the state. These hearings indicated the magnitude of the arthritis problem in the State of Missouri and made recommendations.

Volume III – The Work Group Reports: The third volume of the report describes in detail the formation of six work groups and the reports from each of these work groups.[3]

In 1980, a legislative bill that contained the recommendations of the "State Arthritis Plan" was introduced. After two failed attempts, in 1984 an arthritis act was finally passed and signed into law officially establishing the State Arthritis Program.

Program Goal

To make optimal diagnostic, treatment and rehabilitation services available and accessible to all persons afflicted with arthritis ad related musculoskeletal diseases in Missouri.

Aims

- Establish a network of Regional Arthritis Centers designed to demonstrate and stimulate prompt and effective application of available knowledge for the treatment of patients with arthritis and related musculoskeletal disorders, and
- Develop new knowledge essential for the control of these disorders.

Establishment of the RACs

In 1985 funding was allocated for the Missouri Arthritis Program and according to the recommendations made in Volume I of the report of the Missouri Task Force on Arthritis and subsequent legislation (RSMo 192.700 – 192.727), the Missouri Arthritis Advisory Board (MAAB) was appointed. The MAAB worked together with the Department of Health to develop the request for proposals (RFP) for establishment of RACs. The announcements for the RFP were mailed to all the hospitals in the state and were also advertised in newspapers in the seven regions. There was an overwhelming response to the RFP with 117

Program Description

potential applicants. Of these initial applications 11 formal grant applications were finally submitted. After a thorough review process by a peer review committee, eight RACs were officially designated for seven regions. The Eastern Missouri region received two awards in the City of St. Louis. At the same time the RACs were being designated, the Missouri Arthritis Program received $56,000 in general revenue appropriation to support activities. Block grant funds from 1984 and 1985 also became available for total support of $116,332 for funding the RACs.

Since 1986, the RACs have been an integral part of the Missouri Arthritis Program by providing services for people with arthritis. The RACs are located at hosting institutions, in seven regions of the state that have the capacity to provide comprehensive health care or refer clients to comprehensive health care for individuals with arthritis and related rheumatic diseases. In 1995 the program officially expanded services to children by hiring Juvenile Arthritis coordinators. The RACs have been providing a variety of programs and services throughout the state. Some of the programs and services offered by the RACs are:

- Self management programs,
- Professional education programs,
- Public awareness activities,
- Individual education counseling.

2 Sharp GC, Singsen BH, Hazelwood SE, Hall PJ, Oliver CL: The Missouri Arthritis Program. Legislation, Implementation and funding of a Regional Centers Program. Missouri Medicine 1988, February 79-83

3 Report of the Missouri Task Force on Arthritis to the Governor, the legislature, and the State Board of Health.Volume I: The Plan 1980

4 Report of the Missouri Task Force on Arthritis to the Governor, the legislature, and the State Board of Health. Volme II: The Public Hearings 1980

5 The Missouri Arthritis Program, Missouri Department of Health: Arthritis: the problem, the status, the plan. January 1988

Evaluation Methods

The Department of Health contracted with the St. Louis University School of Public health to conduct an evaluation of the Missouri Arthritis Program. The evaluation was to be comprised of an in-depth qualitative portion as well as a quantitative portion.

Qualitative Methods

The qualitative portion of the evaluation included seven (7) focus groups and individual interviews with each Regional Arthritis Center Coordinator. In addition, an interview with the Manager and Assistant Manager of the Missouri Arthritis and Osteoporosis Program was conducted.

The purpose of the focus groups was to examine specific information and service needs of individuals served by the RACs and to determine the reasons why people used the programs, the benefits they received, and their level of satisfaction. These focus groups also assessed the impact of the Missouri Arthritis Program on the quality of life of individuals with arthritis.

Criteria for participation included anyone who received care through the RACs. Participants for the focus groups were randomly chosen from the mailing list at each of the RACs. Each center coordinator randomly mailed a letter inviting individuals to participate. Number of letters varied from one center to the next and was not recorded. There was an attempt to achieve gender, racial and ethnic diversity. The participants were contacted by mail and invited to participate in the focus group. There was a $20 incentive for participating and refreshments were served prior to the start of each focus group. An experienced moderator who was comfortable with the discussion topics conducted each focus group. The sessions were audio taped, transcribed and analyzed during the summer of 2000.

The RAC coordinators were interviewed in coordination with the focus groups (Summer 2000) to find out about their specific needs and concerns. Most of the interviews lasted approximately ninety minutes and were conducted by the program evaluator.

In-depth interviews were also conducted with the program manager and assistant program manager to get a better understanding of the structure and the processes involved in the management of the entire program throughout the evaluation process.

Evaluation Methods

Quantitative Methods

Quantitative Methods:

Program report data from the RACs were summarized for the years 1995, 1996, 1997, 1998, 1999 and 2000. These reports provided information on:

- Dissemination of arthritis public awareness messages,
- Dissemination of basic rheumatic disease information,
- Proportion of Missourians with arthritis participating in educational, self-help and exercise programs, and
- Continuing educational courses for healthcare professionals.

". . walking better and breathing better than I did nine years ago."

— Participant, Northwest Missouri

Evaluation Results — Qualitative

Interview with Missouri Arthritis Program Coordinators

During the process of the evaluation, in-depth interviews were conducted with program staff to find out about the history of the program and program activities. These interviews were helpful in answering some of the key questions being addressed in this evaluation process.

According to what was proposed in the 1980 Report of the Missouri Task Force on Arthritis, eight RACs were originally established in seven regions of the state in 1985. Currently, there are seven centers in seven regions. Funding was minimal when divided between two centers in Eastern Missouri. The Missouri Arthritis Advisory Board met and discussed this matter in detail and the decision was made to consolidate funding and support one center in Eastern Missouri. These centers are felt to have been instrumental in providing a large number of arthritis and related services throughout the state. Categories of services offered through the RACs are:

- Arthritis public awareness and education,
- Basic rheumatic disease information,
- Rheumatic disease self-management and support, and
- Continuing education for health professionals.

These were the activities that were proposed by the Task Force, and that the RACs have been providing and expanding on since their establishment.

As proposed by the Task Force, the MAAB was also established in 1985 and has been and continues to be an active and important component of the Missouri's arthritis program. The MAAB began with one annual meeting and in 1999 began meeting biannually. The board members and all the RAC coordinators attended these meetings. At each of the meetings the RAC directors report on major RAC activities for the year and any problems they might have had.

According to the recommendations made in the three volumes of the report of the Missouri Task Force on Arthritis, a program manager was hired for the Missouri Arthritis Program in 1985. In 1996, a new program coordinator, Mary Ellen Ankeney, was hired and continues in this position today (October 2001). Having the same program coordinator for over five years has provided continuity and stability to the Missouri

Evaluation Results — Qualitative

Arthritis Program. However, it has been difficult for the program coordinator to manage all the aspects of the program with limited staff. Ms. Ankeney feels that adding at least one additional program staff would strengthen the infrastructure within the program and allow the program manager and assistant manager to focus on the bigger picture and better manage program activities.

Regional Arthritis Center Focus Groups

In 2000, focus groups were conducted at each of the seven Regional Arthritis Centers to better understand the information and service needs of participants using the RACs. Summary results from the focus groups are presented in Table 1 and 2 and key findings are reported below.

The participants who attended the focus groups were either currently receiving care through the RACs or had received care in the past. There was diversity among the participants in respect to gender, and programs they were enrolled in. Since this was a random sample from each area, it is assumed that the participants interviewed in the focus groups were a good representation of the population served by each RAC. Each focus group was approximately 90 minutes long and had an average of 10 participants. There were seven questions asked during the focus group. Once the questions were asked each participant had a turn to respond to the question. This method allowed each participant a fair amount of time to respond to the questions.

The participants were asked seven questions:

1. How did you come to learn about the RAC? Which programs are you currently enrolled in?
2. What information do you find useful?
3. What additional information would you like to receive? Where would you like it from?
4. How have these programs benefited you?
5. Have these programs helped manage your arthritis?
6. Has your quality of life improved as a result of these programs?
7. Are there any barriers to receiving care at the RAC?

Table 1 provides focus group demographics while Table 2 illustrates a summary of the primary information obtained from focus group participants. Details for each focus group question follows the tables.

TABLE 1: NUMBERS ATTENDED AT EACH CENTER AND THE DEMOGRAPHICS OF THE GROUP

RAC	FOCUS GROUP DATE	NUMBER OF PARTICIPANTS	GROUP DEMOGRAPHICS
Southwest Missouri	August 18, 2000	10	All participants were women, nine Caucasians and one African American.
Central Missouri	August 21, 2000	7	All the participants were Caucasian women.
Southeast Missouri	August 23, 2000	11	There were three men and eight women in this group. All participants were Caucasian.
Northwest Missouri	August 31, 2000	9	All the participants in this group were Caucasian women.
Greater Kansas City	September 1, 2000	13	There were five African American women, seven Caucasian women, and one Caucasian man in this group.
Northeast Missouri	September 22, 2000	12	There was one African American woman, ten Caucasian women and one Caucasian man in this group.
St. Louis	December 8, 2000	6	All participants were women, four Caucasians and two African Americans.
TOTAL		68	• 5 men • 63 women • 59 Caucasian participants

Evaluation Results — Qualitative

Table 2. Summary of Information and Service Needs of the RAC

Category	Results
Learned about the RAC	• Friend • Newspaper • Doctor • Support Groups
Useful Information	• All information provided by instructors and speakers • Sharing at support groups
Additional Information	• New research on cures and medications • Information on alternative medicine
Benefits	• Exercise programs helped manage pain • Manage depression • Ability to prioritize • Improved quality of life
Barriers	• Water temperature • Room temperature • Not knowing about the RAC

How did you come to learn about the RAC?

Through a friend: 26% (18) of focus group participants learned about the RAC through a friend.
Newspaper: 15% (10) of participants learned about it through a newspaper advertisement.
Physician: 13% (9) of participants learned about the RAC through their physician.
Flyers: 16% (11) of participants learned about it through flyers at senior centers or medical centers.
Other Sources: 21% (14) of participants indicated they learned about it through either a support group, at a seminar, or from mailings.

Programs enrolled in:

The participants who attended the focus groups were enrolled in various programs offered through the RAC. Many participants were enrolled in multiple programs, i.e., PACE and Aquatics. Some of the participants were enrolled in either the Fibromyalgia or Arthritis Self-Help Course. Other participants participated in either past exercise programs or self-help courses. And yet, others were leaders of support groups or peer instructors in the exercise programs. The chart below illustrates the diversity of the focus groups. However, the chart only reflects the information volunteered by the participants. Many focus group participants never mentioned what class or course in which they participated.

RAC Area	Past or Present PACE	Past or Present Aquatics	Past or Presesnt Self-Help Course	Past or Present Other
Northwest	0	7	1	1
Central	0	0	0	3
Eastern	1	0	2	1
Kansas City Area	6	10	0	0
Northeast	1	0	1	7
Southeast	1	3	0	0
Southwest	3	4	2	5
Totals	**12**	**24**	**6**	**17**

Evaluation Results — Qualitative

What information did you find useful?

Literature: All the participants in the focus groups found the literature distributed by the RAC very helpful. Most of them found the literature (newsletters, brochures, etc.) to be informative and useful.

Speakers: People who had attended seminars and classes found guest speakers to be helpful, interesting and very informative.

Support Group: People who were a part of a support group or had been in the past found that the sharing that occurs during a support group helped them understand their illness better and realize that there were "others just like them".

Instructors: Participants enrolled in the exercise programs or self-help courses found their instructors provided them with very useful information. The participants in the exercise programs said the information on the various exercises affecting different parts of the body proved to very helpful. In addition, learning to pace one's self was noted as being useful by eleven participants.

Manual: The participants in the self-help courses found the self-management manual to be very informative and useful.

Exercise: Twenty-three participants directly stated that the exercise programs were useful to them.

What additional information would you like to receive?

New research: Approximately fifty percent of the participants said they wanted to receive information on the latest research on arthritis or Fibromyalgia.

Medication: Most of the participants said they wanted to get more information on new medication and specific drug interactions. Many of them were taking more than one drug to control their disease and they wanted to know more about the interaction these drugs had with one another.

Alternative Therapies: A few of the participants wanted to know about alternative therapies and wanted more information on holistic healing and natural medication.

The RAC: One thing everyone wanted more information on was, what is offered through the Regional Arthritis Center and where it is offered. They wanted to find out about current programs and how they could enroll in these programs. They also wanted more information on upcoming seminars and classes.

Where would you like it from? (How participants would like to receive information.)

Mail: Most of the participants said they would like to receive most of their information through the mail. They said if the information was sent through the mail to make sure the information was concise and clear. They also wanted the heading to be bold so they would not mistake it for "junk mail".

Instructors: Many participants said they would like to receive new and additional information from their instructors. They all seemed to value the education they received through their instructors and said it would be helpful if their instructors could provide them with this additional information.

Seminars: A number of participants said they would like to receive new information through seminars and talks.

Evaluation Results — Qualitative

How have these programs benefited you?

Almost all the participants said they had benefited from the program in one way or the other. Some of the benefits they received are listed at the bottom of this page.

Mobility: Most of the participants who had participated in the exercise programs said they had increased mobility due to the programs. They said the days they did not attend a session they could not move as well. They said they found a real benefit in all the exercises that they did either in the PACE classes or the aquatic classes.

Ability: Most of the participants who attended the exercises classes or had in the past attended or were currently attending the self-help classes said they were able to "do more" because of these programs.

Not Alone: The participants who were a part of a support group said they realized they were not the only ones affected by the disease and there were others "just like them". Support groups helped them realize they were not alone and this has proven to be greatly beneficial to them.

Have these programs helped manage your arthritis?

A large portion of the participants that directly answered the question (27 participants) indicated that the programs had definitely helped them manage their arthritis. Most of them said the programs helped manage their arthritis by managing their pain. Some others said the programs greatly helped manage their depression. All of the participants said as a result of these programs they had learned to relax more and not stress out over the little things. Participants also stated they learned to pace themselves better and not to overdo things; the programs helped them realize that it as okay to stop and rest and do only as much as they felt they could. Basically, the majority of persons who attended the focus group said these programs were definitely very beneficial in helping him or her manage their arthritis.

Has your quality of life improved as a result of these programs?

Every participant said as a result of these programs their overall quality of life had tremendously improved. Forty-seven (47) of the 68 participants answered yes. Many of the participants noted more than one benefit that improved their quality of life (see table). Many stated they were less depressed because of the programs and, hence much happier. They also felt they had an improved quality of life due to the fact that they had a better social life. People who attended exercise classes together or were in the same support group had gotten to know each other well and they met socially other than in class. Most of them said they looked forward to the classes. It is a place to meet friends and share their troubles and triumphs.

Description	No. of Responses	Description	No. of Responses
Less Pain	12	Feel better	12
More active/more energy	5	Ability to pace ones activities	10
Improved strength	6	Improved sleep	3
Assistive Devices	6	Learned to relax	4
Increased mobility and range of motion	13	Improved mental health: more hope, less stress, don't feel alone	28

Evaluation Results — Qualitative

Are there any barriers to receiving care at the Regional Arthritis Center?

Most of the participants found no major barriers to receiving care at the RACs. Some of the lesser barriers they found were:

The RAC: Many of them said they did not know about the program, which was a barrier. They said if the program was better advertised they would find it easier. Most of them had found out by word of mouth, and if they had not had that friend telling them about it there was no way of finding out about the program.

Distance: A few of the participants found they had to travel a long distance to attend programs and it was difficult, as many of them did not drive anymore. They had to rely on someone else for transportation. They suggested having more classes in senior centers where it would be easy for them to attend.

Temperature: Water temperatures in the pools were too cold for the people in the aquatic classes. They said the water, as well as the changing room, was too cold. This was a barrier as it made them not want to get into the water and participate in the class.

Focus Group Finding Summary

The focus groups strongly indicate that the programs offered through the RACs are very beneficial to people with arthritis. All the people who attended these focus groups found that they had definitely benefited from the program and these programs had positively helped them manage their arthritis or fibromyalgia. The programs had also significantly improved their overall quality of life.

"I think just the fact that most of us aren't aware of the Center is a barrier to accessing a lot of the programs and services."
— Participant, Eastern Missouri

Evaluation Results — Qualitative

Interviews with Seven (7) RAC Coordinators

The coordinators at the RACs were interviewed to determine their specific needs and concerns. Most of the interviews lasted approximately ninety minutes. The responses to most of the questions were similar across the board with most of the RACs facing similar concerns.

When asked which services were most beneficial, most of the coordinators said that all the services were beneficial but especially the self-help courses; the exercise programs and the support groups were the most beneficial programs in their opinion. Although they found the self-help courses to be beneficial to people with arthritis, they had not had much success in enrolling people for these courses. A lack of awareness about these courses was said to be the biggest problem in all the areas. All the RACs were using various sources of media such as, newspapers, flyers, mailing lists, newsletters and brochures, to promote their programs but felt that they were still not reaching as many people as they could serve at each RAC. The coordinators felt that increasing awareness of their programs was the only way they could increase enrollment in the self-help courses and the other programs offered through their RAC. Some of the other barriers to enrollment were inadequate physician referral to the programs, distance of the RAC office from other counties, financial constraints of people with arthritis and transportation to attend the classes.

Most of the RACs do not have a database to keep track of the people they were serving. Headcounts are the most common method of keeping track of the number of people attending the various programs. The coordinators did express an interest in setting up a database but staffing a person to manage the database is a barrier. Staffing is an issue for all seven RACs. They do not have the resources to fund a full time position and this is a real concern for the coordinators. Some of the RACs depend heavily on volunteers to carry out RAC functions like send out mailings, conduct classes, and manage support groups etc., while others depend on their host institutions for support.

All the RACs have an advisory board comprised of key members in the community and have partnered with numerous local agencies forming a network to provide services that can be accessed by people with arthritis.

RAC Perspectives

1. The most beneficial programs are the exercise programs and self-help courses.
2. Lack of awareness about exercise programs and self-help courses is the biggest problem.
3. Staffing levels is a concern for program implementation and reporting.

Evaluation Results — Quantitative

Quantitative data collected for the Missouri Arthritis Program include, 1999 BRFSS data, 1999 Missouri Arthritis Program/Regional Arthritis Center Needs Assessment Survey and program report data. The survey and the program data will be discussed here.

Table 3 summarizes the results from the Missouri Arthritis Program/Regional Arthritis Center Needs Assessment Survey. The survey was mailed to participants in each Region. The survey tool, developed by MAOP's manager and research analyst was mailed from each RAC center. Each RAC sent between 100 and 250 letters and surveys. One thousand one hundred (1,100) surveys were mailed and 418 surveys were returned for a response rate of 38%. Three hundred and ninety-four (394) respondents completed the entire survey. The maximum number of respondents were from the Southwest RAC. Most of the respondents (60.1%) obtained their arthritis information from their health care professionals. When asked what type of arthritis program they would be most likely to attend, 56.1% said they would be most likely to attend a physical activity program and the main reason for them attending an arthritis program was to increase muscle strength and flexibility (66%). Almost 50% of those surveyed said nothing prevented them from participating in arthritis programs.

Program report data from the RACs were summarized for the years 1995, 1996, 1997, 1999 and 2000. These are reported in table 4 and 5. The program report for 1995-98 varies from the 1999-2000 report. The variance in the reports is due to internal reporting changes. These reports show the number of people participating in rheumatic disease self-management exercise programs has increased but the participation in the self-help course has decreased significantly. Number of minorities participating in these programs and the number of underserved participants in these activities increased from 7,432 in 1999 to 10,246 in 2000. The number of individuals served is actually the number of service encounters. For example, if Jane Doe enrolls in the six-week P.A.C.E. course and attends five of the sessions, then she has accessed or encountered the service five times. The number of individuals served by the RACs increased substantially from 140,316 in 1999 to 224,757 in 2000. But the number of professionals receiving educational programs decreased from 1999 to 2000. The number of professional education programs offered throughout the state increased from 161 to 189 but the number of participants in these educations decreased from 3,995 to 3,522.

Media services, press releases and PSAs have increased greatly from 1,198 in 1999 to 4,119 in 2000. Media activities have steadily increased since 1995.

". . . It has helped me and it also has made me more conscious of the fact that there is a lot you can do for yourself."

— Participant, Central Missouri

Evaluation Results — Quantitative

Table 3. Missouri Arthritis Program/Regional Arthritis Center Needs Assessment Survey Number of Respondents = 394

- Number of Respondents from each Regional Arthritis Center
  - 0 – Central (Columbia)
  - 62 – Northeast (Kirksville)
  - 48 – Southeast (Cape Girardeau)
  - 59 – St. Louis
  - 10 – Kansas City
  - 86 – Northwest (St. Joseph)
  - 129 – Southwest (Springfield)

- Where do you generally obtain information about arthritis? (Check all that apply.)
  - 60.1% – Health Care Professional
  - 8.8% – Library
  - 32.5% – Television
  - 27.6% – Arthritis Foundation
  - 19.6% – Friend
  - 53.4% – Magazines and Newspapers
  - 39.7% – Regional Arthritis Center
  - 13.4 % – Other (37.7% – Internet)

- What type of arthritis program would you be most likely to attend? (Check all that apply.)
  - 31.6% – Support Groups
  - 56.1% – Physical Activity Program
  - 4.5% – Arthritis Phone Service Interventions
  - 23.4% – Lecture/Workshop
  - 41.6% – Arthritis Self-Help Course
  - 35.5% – Weight Control Program
  - 5.3% – Bone-Up
  - 7.6% – None

- What are the most important reasons for you to attend an arthritis program? (Check all that apply.)
  - 52.7% – Pain Management
  - 23.3% – Social Support
  - 66.0% – Increase Muscle Strength and Flexibility
  - 4.9% – Other
  - 43.0 % – Education/Information
  - 23.8% – Don't attend arthritis programs
  - 12.0% – Education for Family Members

- Which of the following prevent you from participating in arthritis programs? (Check all that apply.)
  - 9.0% – Transportation
  - 0.8% – Couldn't get a Referral
  - 47.1% – Nothing prevents me from participating
  - 13.2% – Don't know where to find out about programs
  - 15.1% – Other
  - 12.1% – Too Busy
  - 6.3% – No one to go with me
  - 12.6% – No program in my area
  - 14.2% – Cost

- Does your arthritis limit you in any of these activities? (Check all that apply.)
  - 14.2% – Self-Care Tasks
  - 34.7% – Work
  - 43.4% – Mobility
  - 48.4% – Household Tasks
  - 32.1% – Social Activities
  - 29.7% – My arthritis does not limit me

- Demographics
  - 90.1% – Female
  - 90.1% – White
  - 1.4% – Other
  - 5.1% – Age 18-34
  - 13.3% – Age 35-49
  - 36.8% – Age 65-79
  - 9.9% – Male
  - 8.6% – Black
  - 13.3% – Age 32.7%
  - 32.7% – Age 50-64
  - 12.0% – Age 80+ years

Table 4. Missouri Arthritis Program/Regional Arthritis Center Program Report Data (1995-1997)

Program Area/Activities	1995	1996	1997
Arthritis Public Awareness			
Media Services (Total Articles/Interviews)	131	107	103
Press Releases & PSAs Distributed (Total Releases/PSAs)	349	137	1,250
Health Fairs/Exhibits (Total Fairs & Exhibits)	76	92	76
Kids on the Block Programs (Persons Attending)	2,718	3,664	4,817
Public Forums/General Presentations (Persons Attending)	7,278	4,311	7,466
Basic Rheumatic Disease Information			
Literature Distribution (Pieces Distributed)	34,415	32,635	37,70
Newsletters, distributed by the RAC (Newsletters Distributed)	65,049	56,313	55,649
Requests for Information, phone or walk-in (Total Requests)	4,630	7,572	5,160
Referrals to Other Organizations (Total Referrals)	1,026	822	715
Loan Materials, books, videos, etc. (Persons Receiving Materials)	1,203	750	688
Individual/Family Education (Persons Receiving Education)	990	1,108	1,473
Seminar, Workshops, for persons affected by arthritis (Persons Attending)	1,987	1,091	1,719
MO Arthritis Research Rehabilitation Training Center (Internet Hits)	na	na	288,063
Rheumatic Disease Self-Management & Support			
Support Groups (Total Attendance — all sessions)	3,049	1,978	2,485
Arthritis Self-Help Course (Total Attendance — all sessions)	1,345	356	486
AF/YMCA Aquatics Program (Total Attendance — all sessions)	24,702	9,361	21,674
— Other Aquatic Exercise Programs (Total Attendance — all sessions)	1,378	1,961	1,395
PACE Exercise Program (Total Attendance — all sessions)	10,378	7,065	18,491
— Other Land Exercise Programs (Total Attendance — all sessions)	18,180	9,495	25,150
Fibromyalgia Self-Help Course (Total Attendance — all sessions)	na	1,247	1,070
Leadership Trainings	na	na	33
Individuals receiving Leadership Training	na	na	207
Minority Participation in Self-Management Activities	na	na	1,098
Continuing Educational Courses-organized by RAC personnel			
Greater than or equal to 4 hours in length (# of Training Sessions)	na	na	13
Physicians, non-rheumatologists (Total Attendance)	1,944	1,385	345
Rheumatologists (Total Attendance)	1,033	988	8
Allied Health Professionals (Total Attendance)	741	830	522
Less than 4 hours in length (# of Training Sessions)	na	na	185
Physicians, non-rheumatologists (Total Attendance)	na	na	1,165
Rheumatologists (Total Attendance)	na	na	1,424
Allied Health Professionals (Total Attendance)	na	na	1,208

Evaluation Results — Quantitative

Table 5. Missouri Arthritis Program Data Report (1999-2000)

Program Area/Activities	1999	2000
Annual Report (BRFSS)		
[PERIODIC] Prevalence of arthritis	26.3%	26.1%
[PERIODIC] Percent of Missourians with activity limitation due to joint symptoms	12.7%	11.9%
Quarterly Report Data (Reflects cumulative total for all four quarters):		
Delivery of arthritis-related services by RACs to 85,000 individuals	140,316	224,757
# of individuals served through MAOP that report improvement in their condition	Pending	Pending
# of children with rheumatic diseases who receive service coordination services	73	77
# of community-based disease management and support activities	777	1,019
Attendance (encounters)	140,316	224,757
# of community-based public awareness activities/Attendance (encounters)	99/29,037	159/22,150
# of professional education programs/Attendance (encounters)	161/3,995	189/3,522
# of minorities participating in disease management/support activities (encounters)	3,890	5,364
# of minorities participating in disease awareness & ed activities (encounters)	5,736	2,527
# of pieces of literature distributed	71,285	66,919
Additional Information		
# of Primer's distributed	249	245
Leadership Trainings/Attendance	27/219	27/219
Individual/Family Education	1,138	2,061
# of underserved participants in disease management/support activities	7,432	10,246
Media Services	62	572
Press Releases/PSAs	1,198	4,119

Program Costs

Initially most of the funding for the Missouri Arthritis Program came from Arthritis General Revenue and PHS Block Grants. In 1995, when the Juvenile Arthritis Program was officially established, money from MCH block grants was made available for the program. In 1997, the Osteoporosis program was established and the program name was changed to the Missouri Arthritis and Osteoporosis Program, and money from osteoporosis general revenue was added to the budget. In 1999 the Missouri Arthritis and Osteoporosis Program received a four-year grant from CDC and another $287,000 was added to the program budget.

Evaluation Results — Quantitative

The money that is received for the program is used for program costs, including personnel and operating expenses, is distributed to each of the RACs. The RACs initially received $31,000 and now this amount has been increased to $48,000. This money is used by the RACs to provide programs and services, and to pay personnel costs. All of the money is used by the RACs and there has not been a time where they have turned back money. For some RACs, this money usually pays for only a part of the RAC coordinators salary and the rest of their salary is paid through their hosting institution. The hosting institution also provides the RACs with other in-kind support.

Fiscal Year	State	Federal	Other	Total
1987	63,050	60,075		$123,125
1988	61,110	90,075		$151,185
1989	62,080	54,045		$116,125
1990	62,080	90,075		$152,155
1991	64,844	90,075		$154,919
1992	64,844	110,075		$174,919
1993	103,644	110,075		$213,719
1994	103,644	110,075		$213,719
1995	103,644	110,075	140,000	$353,719
1996	103,644	105,575	140,000	$349,219
1997	181,947	110,075	140,000	$432,022
1998	90,370	223,890	140,000	$454,260
1999	235,862	145,075	155,000	$535,937
2000	231,435	420,731	155,000	$807,166

". . . I like the information coming by mail. Sometimes in our exercise class when others share the experiences that they've just recently had, that is also very helpful. I personally would like to know more about alternative medication. Not so much the wonder drugs because I want to get away from so many medications that I have to take already for other problems. I am interested in other areas of natural medicine and health."

— Participant, KC Missouri

Conclusions & Recommendations

The Missouri Arthritis Program was established in 1984 and has been serving the needs of people with arthritis in the State of Missouri since then. All MAOP services are offered through the seven RACs. The effectiveness of the RAC was evaluated through focus groups and interviews with the RAC coordinators and through in-depth interviews with the Missouri Arthritis Program Coordinators. The Missouri Arthritis Program/Regional Arthritis Center Needs Assessment Survey and the program report data support the focus groups and interviews.

From the focus group it was clear that the best way to make people aware of the RAC was through newspaper advertisements and by word of mouth. Other support groups were also very instrumental in letting people know about the RAC. All information provided by self-help course instructors and speakers at seminars was found to be very useful. Participants also found the information they received through sharing experiences in support groups to be very beneficial. Although they received a lot of information, participants wanted to receive more information on current research, new cures, and new medications.

Almost all of the participants said they had benefited by the various programs offered through the RAC. Participants stated the exercise programs and the self-help classes had benefited them by helping them manage their pain better and also manage their depression. They also said the classes had helped them tremendously by teaching them how to pace themselves and helped them learn to prioritize their everyday activities. This changed the way the viewed their disease and their life and helped them achieve an overall better quality of life.

Some of the barriers encountered were the temperature of the water in the pools and the rooms. Participants also felt family members who did not understand their condition were barriers. Efforts need to be made to see that pool temperature is optimum for people with arthritis so they can exercise without that barrier. Also holding seminars or support groups for family members would be helpful for family members to better understand arthritis.

Another barrier the participants had was the fact that they were not aware of the services offered through the RACs. Many participants who attended the focus group said that not knowing where to go to receive services was a major barrier. The RACs need to increase public awareness of the services and programs being offered. Finally, more physicians need to be aware of the RACs in their area and the importance of referring their patients to the RACs.

The seven focus groups strongly indicate that the programs offered through the RACs are very beneficial to people with arthritis. All the people who attended these focus groups found they had definitely benefited from the program and these programs had positively helped them manage their arthritis or fibromyalgia. The programs significantly improved their overall quality of life. These focus groups also found the RACs are an effective way to achieve the aims of the Missouri Arthritis Program.

Although program report data show there has been an increase in the media services, press releases and PSAs, the focus group findings suggest that there needs to be more done in regard to increasing awareness about the RACs. People need to be able to associate arthritis services with the RACs and vice versa. They need to be made aware of the existence of the RACs in their area and the types of services offered through the RACs. Only then can the services offered through the RACs be utilized to their full potential.

Another recommendation of this evaluation is to establish a standardized database for all the RACs to track courses offered and participation of persons with arthritis. Presently, there is no existing database available for the RACs and hence there is no way to track individuals who receive services through the RACs. A standardized database will enable the RACs to track number of people utilizing their services and get a better understanding of how people learn about their services. A database will also be helpful in determining physician referrals number of programs a person participates in. This would be helpful for future evaluations of the RACs.

Without support staff, it is very difficult for the RAC coordinators to support a database. So, increased funding needs to be provided to the RACs so they can hire support staff to enable them to collect and manage their data.

The number of health professionals receiving continuing education needs to be increased. The Missouri Arthritis Program/Regional Arthritis Center

Conclusions & Recommendations

Needs Assessment Survey found most of the respondents received their arthritis information from their physicians; therefore it is very important that the physicians are made aware of arthritis services, the RACs, and standards of care for people with arthritis.

The RACs have been an integral part of the Missouri Arthritis Program in addressing issues relating to arthritis. According to the recommendations made in the three volumes of the report of the Missouri Task Force on Arthritis, a program manager was hired for the Missouri Arthritis Program, the Missouri Arthritis Advisory Board (MAAB) was appointed, and RACs were established in seven regions of the state. These centers use a multidisciplinary approach in helping people with arthritis manage their condition. Increased support needs to be provided to these institutions so they can continue to strengthen their efforts to impact the problems associated with arthritis and other rheumatic diseases.

This evaluation has shown that the Missouri Arthritis Program has been successful in achieving what they were set up to do and should be considered as a national model for arthritis care within public health. However, additional evaluation is needed to assess the process, impact and outcome of the Missouri Arthritis Program.

MAOP has met aims outlined at the onset of the program by the Task Force, including the establishment of a Regional Arthritis Center system; the establishment of a Missouri Arthritis Advisory Board; and providing physical activity, self-management, and educational forums for people with arthritis and their families; as well as remaining current on arthritis related issues including treatment and self-management techniques.

The organizations of the RACs and the funding streams seem to be a good way to achieve the aims of the arthritis program. However, further evaluation is needed to better understand implementation, funding, and if there are methods of implementation that can be improved or enhanced and if funding is adequate to truly reach the target population.

Awareness of the RACs varies, though overall, this is a weak area of the program. Many individuals do not realize that the services they receive are from the RAC. Some confuse the RAC with the Arthritis Foundation.

Focus group members were very satisfied with the information and services they were receiving including materials and assistance with managing their arthritis. One barrier that was prevalent when discussing the aquatics programs was water and room temperature; often the temperatures were too cold.

Several issues of the RAC System still need to be evaluated. Issues include: Is the RAC system effectively and efficiently providing programs and services within their respective regions? What are common approaches, standards, and components of each RAC office? Are there additional barriers to program implementation and expansion? Is the system working well? What can be improved or enhanced? What needs to change? What is the penetration of the program? Is funding adequate for the system to meet the needs of Missourians with arthritis? Has funding had an impact on the programs over the years? Is the program cost effective? To comprehensively assess the program, additional focus groups, interviews, evaluations, and statewide surveys may need to be conducted to completely evaluate the impact and outcome of the program and assess if the program is achieving its mission "to promote optimal quality of life for all Missourians affected by arthritis or other rheumatic conditions through early interventions, education, service, and collaboration".

"The water temperature in the swimming pool was a major barrier."

The only barrier that I can really think of is distance."

— Participants, Southwest Missouri

Notes

Notes

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