



# ARTHRITIS COMMUNITY RESEARCH & EVALUATION UNIT (ACREU)

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## EDUCATION NEEDS OF CLIENTS WITH RHEUMATOID ARTHRITIS: A FOCUS GROUP EXPERIENCE

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## **Education Needs of Clients with Rheumatoid Arthritis: A Focus Group Experience**

### **I: Introduction**

Education is generally recognized as an important part of a comprehensive treatment program for people with rheumatoid arthritis (RA). It has been suggested that in chronic conditions such as RA, education is one way of enhancing both physical and psychosocial outcomes. Randomized controlled trials of educational programs have demonstrated decreases in pain, depression and disability and increased compliance and other behaviours believed to positively affect the health status of people with arthritis (1-8). The literature suggests the effects of education programs for people with arthritis occur above and beyond any improvement due to medications (9,10).

The need for education exists in clients with many types of chronic illness. However, it is particularly important in clients with RA who may, for the rest of their lives experience a series of flares and remissions. Furthermore, the course of pharmaceutical treatment is not clear and definitive, and outcomes vary among individuals. Therefore, the ability of clients to develop positive coping skills would more likely be enhanced by the knowledge and understanding they have regarding their disease, than by any particular course of medical treatment.

Education is an important component of any treatment program for RA. Community based health professionals of The Arthritis Society, Consultation and Therapy Service (CTS) have long recognized the need for comprehensive education to help clients cope effectively with this chronic condition. This fact was confirmed through a systematic review of the charts of clients referred to the CTS (ref). Lack of knowledge of the disease and its management was identified as one of the most frequently recorded problems requiring intervention.

### **II: Literature Search**

To evaluate the efficacy of the educational intervention provided by the CTS, a decision was made to assess clients' knowledge via a knowledge questionnaire. Existing questionnaires which measured knowledge of disease and disease management in individuals diagnosed with RA were examined. A literature search using Medline was conducted (1966 - present, English only). All appropriate articles were reviewed. The search strategy included: arthritis, musculoskeletal disease, education, patient education, consumer education and program evaluation. Only two self-administered questionnaires which had received any formal validation were identified ref.

Although it has been suggested that psychosocial issues are an important component of

educational programs (13), neither questionnaire explored these issues in any depth. Nearly half of the questions were related to etiology, laboratory tests and symptoms. Some questions on medications were out of date or did not apply to all clients.

Although other investigators reported the use of knowledge questionnaires, they are often not described in sufficient detail to evaluate their content validity and applicability to a home therapy educational intervention. Most are developed to measure content of a specific program and have not been tested rigorously for reliability and validity (14 - 19). We did not identify any outcome measures used to measure knowledge in a community setting.

The decision was made to develop a knowledge questionnaire which would include items related to self-management, have specific applicability to clients receiving physiotherapy, occupational therapy and social work in the home setting and which would address psychosocial issues.

This report presents the results of a study to identify the learning needs of people with RA in order to develop a knowledge questionnaire. Development of the knowledge questionnaire is ongoing and will be reported at a later date.

### **III: Methods**

As a first step in developing the questionnaire, focus groups were used to identify key learning issues for clients with RA. A secondary purpose was to explore the difference, if any, in learning needs between clients with early and longstanding disease.

Six focus groups were held over a three-month period. All participants had a confirmed diagnosis of RA. The groups were led by a person with experience in facilitating groups (AH). Proceedings were tape-recorded and notes were taken by SL. Each group was two hours in length.

Group members were told in advance about the general topic but they were not provided with any detail regarding the actual questions. The meeting was conducted by the investigators (AH and SL), who posed a series of nine structured open-ended questions. The questions were developed by AH and SL. Input was provided by other health care professionals working in rheumatology, the social sciences and epidemiology. Questions explored the areas of learning needs at diagnosis, family learning needs, helpful and unhelpful information, unmet learning needs, current learning needs and key sources of arthritis information. Group members were told that there were no right or wrong answers and that it was not a consensus process. A full range of responses were encouraged and all group members had the opportunity to participate. The leaders encouraged participants to interact with each other and did not express opinions or judgments.

The first group (n = 6) was used as a pilot to test the questions and the process. This group consisted of CTS clients who knew each other well through participation in an informal

support network. They provided feedback regarding both content of the questions and format of the discussion. Revisions were made and the final list of nine questions is appended (Appendix 1). The next three groups were composed of clients identified by CTS therapists; two groups of clients with late disease (n =9), defined as more than two years duration and one group with seven clients with early disease (two years or less). Since men were under-represented in our sample, a fifth group (n = 5) was held with men, identified from the practice of a rheumatologist in an area where there were no CTS services available. In addition, four health care providers representing nursing, occupational therapy and medicine, with a mean of 4.8 years experience in rheumatology, were brought together to discuss modified questions on the same topic.

An independent content analysis of notes and tapes was conducted by SL and AH to identify themes within and between the groups.

#### **IV: Results**

A total of 27 people with RA participated in the client groups. All were seeing a rheumatologist. Over 70% were female. The mean age was 47.9 years varying from 29 to 67 years. Mean disease duration was 9.4 years (3 months to 46 years). Just over 18% had early disease. Clients were generally well-educated with a mean of 11.7 years of formal education. Table 1 presents the demographic characteristics of the client focus group participants.

Participants were eager to attend the focus groups and most were candid in discussing their reactions and feelings. Although apprehensive initially, most people participated freely and it sometimes proved difficult to accomplish the task in the allotted time because of the number of opinions expressed. The responses can be summarized as follows:

##### **1. Learning Needs at Diagnosis**

At the time of diagnosis, most people reported a sense of relief coupled with fear about the future. They were relieved that RA was not generally life-threatening and that their illness finally was given a name. Concerns about becoming totally disabled and fears of such things as being "bent and twisted" arose in their minds. Much of the worry related to the clients' past experiences of seeing or knowing someone with RA, e.g. one participant's sister had RA and died from a reaction to her medications. This frightened her and reluctant to try any medications. Many clients envisioned "worst case scenarios" after their diagnosis and catastrophized about what the future would bring. eg ending up in a wheelchair. They had concerns about their ability to care for their family, to work and to continue their previous lifestyle.

A major concern for most at the early stages of the disease was pain management. Clients at this early stage had expectations that the medications would work and expected that the rheumatologist would tell them everything they needed to know about their arthritis. In

general, participants wanted more information about the disease, their medications and the side effects and how to control pain.

A difference was noted between the responses of female and male participants. Females tended to describe their reactions to diagnosis in emotional terms saying they were very "upset", "crying" and "feeling severe distress". The men tended to describe their experience in more functional terms e.g. "I couldn't work any more", "I had to give up golf." and did not as readily express emotional responses.

Next to health professionals, participants reported that the library was a good source of arthritis information when they were first diagnosed.

## **2. Family Learning Needs**

Many participants indicated that family members had similar concerns. The families' reactions to diagnosis also depended on their previous experience with others with arthritis. It was noted that family members have their own needs for education and support and it was recommended that they be included in educational sessions, both in individual sessions with a health-care professional and in more formal group sessions. It was felt that culture, family attitude and knowledge played an important part in disease management and outcome. Written material geared to the needs and questions of family members was suggested.

Several participants noted that family members, friends and co-workers continued to have high expectations of them. They referred to the problem of having an "invisible disease", i.e. pain, stiffness and fatigue but no signs of deformity in the early stages. This raised issues of credibility at home and at work.

## **3. Most helpful things they learned**

When asked what were the most helpful things people had learned, practical skills such as energy conservation, joint protection, pacing, where to get adaptive devices and "gadgets" were all mentioned. There was a strong endorsement of rest as an important and legitimate form of treatment.

Most with longstanding disease had learned not to expect drugs to "do it all". They had learned the importance of self-management strategies.

Early consultation with a rheumatologist was considered essential and the relationship with the rheumatologist was an important one. They felt that the rheumatologist provided information regarding the spectrum of available treatments particularly in the area of pharmaceutical interventions. They liked being able to discuss their questions and concerns in an open, egalitarian manner and to feel free to disagree if they felt strongly about an issue. Many mentioned feeling "rushed" through their appointments and some had switched rheumatologists if they felt they didn't get answers to their questions.

Peer support groups were considered a valuable tool both for providing emotional support and for educating clients about practical lifestyle issues, as they provided an opportunity to share feelings and ideas with others who could relate to their experience. Both group leaders noticed that even the focus group became a peer support group of sorts over its two hour duration. Participants shared ideas, exchanged phone numbers and thanked the leaders for allowing them to attend such a group, reporting that it was "great" to have an opportunity to talk to others in the same situation.

#### **4. Unmet Learning Needs**

Information about arthritis medications and their side effects was the most frequently identified area where they had difficulty getting information. Many had learned through trial and error. "It's a real crap shoot." They saw the rheumatologist as the main source of this information, but recognized that he/she didn't have the time to provide the education. Few identified the pharmacist as a source of information.

Information about community resources was difficult to find, particularly information about rheumatologists, pool programs, support groups, job retraining, disability pensions and the eligibility for Home Care.

Often, participants reported that once they were diagnosed with RA, family doctors tended to blame their arthritis for other medical problems e.g. chest pain. Those with longstanding disease had learned to really pay attention to their bodies and to get a second opinion when unsure of their symptoms. "Everything gets blamed on arthritis".

Many participants expressed frustration around finding out about the options for surgery. They reported conflicting information and recommendations from family doctors, orthopaedic surgeons and rheumatologists. Many who had had surgery wished they had been offered the option sooner. They often postponed surgery because of conflicting information and wished they had done it sooner.

#### **5. Unhelpful Information**

Almost all participants acknowledged that they had used "unproven remedies" at some time usually under pressure from family or friends. They felt that if they did not try them, they would be regarded as unmotivated or unwilling to get better. They felt that more education would make them less vulnerable to influence by those who promoted such remedies. They also wanted more information regarding the use and success, of such remedies, if any.

Participants with early disease did not want to see people in wheelchairs or with severe deformities. This created more fears and anxiety.

Often participants reported receiving too much information early on in their disease i.e.

information overload. One client used the term "arthritis of the brain" to describe her inability to receive and absorb educational information when she was in a flare. Information overload is a very real risk and education must be provided on a gradual, logical and organized basis. The timing of when they received information was important. Family members played an important role when a lot of information was delivered, often remembering things that the client forgot. Written information to take home was also seen as useful when there was a lot of information to absorb.

## **6. Current Learning Needs**

There was a difference noted between the knowledge needs of those with early disease and those with later disease. Those with early disease were much more preoccupied with the emotional reactions to the diagnosis and the impact on lifestyle, particularly earning a living. They had more questions about prognosis and about treatment alternatives. Those with later disease were not as worried about the future. They were more preoccupied with maintaining life skills and hence a good quality of life. They needed information about ongoing pain management, maintaining mobility, general coping skills and the practical issues of activities of daily living such as sleep positions, footwear, assistive devices and sexuality issues.

Clients who had early and ongoing contact with a wide variety of health care professionals felt that they developed more knowledge and coping skills related to their disease. They recommended earlier referral to community programs such as support groups and pool programs. Those in the early stage of the disease expected the physician to answer all their questions and to manage their disease. Those with later disease had learned that they needed to manage their own disease and that there were many resources available in the community to help them do that on an ongoing basis.

Participants indicated a need for ongoing educational programs geared specifically to their stage of the disease and their stage of life i.e women with small children wanted to be in groups with other women with small children coping with the disease.

## **7. Things they wished they had learned sooner**

All participants said they wished they had seen a rheumatologist sooner. Others noted that they wished they had been referred to pool programs and support groups sooner. Many said that it had taken them a long time to realize the importance of rest and pacing themselves in managing their disease. Most with longstanding disease said they wished they had learned the importance of helping themselves sooner.

## **V: Discussion**

Any education that is done with people with RA must be done gradually and be geared to each individual's needs. Issues such as ethnic background, learning style and educational level must be taken into consideration when planning an educational program. If the client is

in pain or feeling physically unwell, they may not be able to absorb as much information as they can when their pain is being managed effectively.

Education should be provided in a variety of ways, through individual sessions with a health professional, formal classes or through contact with others with RA. Didactic, participative approaches and written educational materials were acceptable and met the needs of people with different learning styles.

Psychosocial issues as well as physical management issues should be addressed in any educational program. Where possible, family members should be included. Education should be geared to the particular needs of the individual and not create "information overload". Information should be practical and relate to skills of daily living.

Topics such as the emotional reaction following the diagnosis, depression and mood changes, reaction of family members, development of a support system and living with a chronic illness must be addressed. Other preferred content areas mentioned included learning about relevant community resources, sexuality, and lifestyle issues.

Contact with others with RA was strongly recommended, either individually or through support groups, however these people should be in a similar stage of life and coping with similar problems.

Early contact with a variety of health-care professionals and community resources was considered important. Contact with a rheumatologist was considered essential.

## **VI: Conclusions**

From the focus groups, seven content areas were identified as crucial areas for learning:

- prognosis/outcome of RA,
- pain management,
- joint protection,
- energy conservation,
- exercise,
- psychosocial issues (coping strategies/feelings) and •medications.

Questions relating to these areas will be included in the knowledge questionnaire.

People with early and late disease have different learning needs, therefore educational interventions need to be targeted to the needs of people at different stages of the disease. At diagnosis, more emphasis should be placed on client concerns about prognosis and psychosocial issues. The client's and family's emotional response to the diagnosis of RA seem to depend on their previous experience with others with arthritis. This should be



explored early on in the educational process. Clients and family members have similar concerns and educational programs need to address the concerns of both groups.

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# Pilot Work to Inform the Choice of Outcome Measures for Arthritis Hydrotherapy Programs

## Focus Group Questions -February 27, 1995

1. **Please tell us why you decided to come to the pool program?**
  - *doctor/other told me to come*
  - *love swimming*
  - *read about program*
  - *my idea*
  - *need the exercise*
  - *can't tolerate medication*
2. **Has the pool program done anything for your arthritis in any way?  
Please explain.**
  - *joints*
  - *pain*
  - *stiffness*
  - *mobility*
3. **Has the pool program had any effect on your general health?  
In what way?**
  - *mood*
  - *social life*
  - *confidence*
  - *mental well-being*
  - *activities of daily living*
  - *outlook*
4. **When you attend the pool program, how do you feel the next day?**
5. **Is exercising in water different from other types of exercise?  
If yes, in what way?**
  - *specific benefits compared to other types of exercise*
6. **What do you like best about exercising in water?**
7. **Is there anything that you don't like about exercising in water?**
8. **If you miss a session in the pool, does it make any difference?  
If so, what?**
9. **What exercise do you like best?**
10. **Is there anything else you'd like to add?**