

**ACREU**



Arthritis Community Research & Evaluation Unit

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**University Health Network**

**LIVING WITH ARTHRITIS: SELF-  
MANAGEMENT STRATEGIES IN  
THE CONTEXT OF CHRONIC  
DISEASE MANAGEMENT**

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# Executive Summary

This report presents findings from a qualitative study of people with arthritis in Ontario. The study was conducted to provide insight into the daily lives of people who live with arthritis and the self-management strategies they use to manage their disease in the community. Given the current emphasis on chronic disease management, this report attempts to set arthritis self-management strategies in the context of broader chronic disease management.

## Key Findings

- A qualitative study of 19 adults with a diagnosis of arthritis in Ontario was conducted. Participants had a mean age of 56 years and were predominantly female.
- Participants reported that arthritis had a broad impact on all aspects of their daily lives. Six themes emerged to describe the impact of arthritis: activities of daily living; community, leisure and social participation; work; family; financial management; and emotional well being.
- The self-management strategies participants described to manage their arthritis were grouped into the following most common strategies:
  - Information and Education
  - Activity and Behaviour Modifications
  - Environmental Changes
  - Exercise
  - Assistive Devices and Aids
  - Orthoses
  - Nutrition
  - Conventional Medications
  - Topical Treatments
  - Alternative and Complementary Care
  - Social Support and Positive Thinking
- Participants reported previous and/or ongoing consultation with health care providers such as primary care physicians (n=19), physiotherapists (n=17), and rheumatologists (n=14). Participants also sought out community resources to help them self-manage their disease including The Arthritis Society, support groups, exercise and pool programs.
- The financial and emotional stresses reported in this study presented challenges equal to the physical challenges for many participants. These findings are similar to those found in other research and suggest that care for people with arthritis should extend beyond physical disease management and include emotional support.
- An integral component of a model of chronic disease management is integration of health services, education and advice to support and empower people to manage their disease. Some self-management strategies are disease-specific (e.g. joint protection) while others are more general to all chronic diseases (e.g. social support, problem solving skills).
- It is key that health care providers be aware of resources outside the health care system, such as peer support, self-management/education programs and community programs that may assist people to self-manage their condition.

# 1.0 Introduction

Arthritis is among the most prevalent chronic conditions in Canada and is the leading cause of pain, physical disability and health care utilization<sup>1-4</sup>. Arthritis also affects wide aspects of life such as labour force participation, leisure, travel and social activities<sup>3,5-7</sup>. There is no cure for most types of arthritis but treatments exist that have been shown to prevent disability, maintain function and reduce pain associated with arthritis<sup>8-11</sup>. A number of these interventions are embedded within the health care system, including consultation with a rheumatologist for pharmacologic interventions for people with rheumatoid arthritis and orthopaedic surgery for people with end stage arthritis. In recent years, there is an increased awareness that much of health care for chronic diseases is self-care or self-management by patients themselves<sup>12</sup>. As a result, self-management and education programs have become increasingly popular. Governments are striving to improve chronic disease prevention and management, with recognition of the importance of empowering patients to build skills for healthy living and coping with diseases such as arthritis<sup>13</sup>. Gaining an understanding of the impact of arthritis and how self-management strategies are integrated into the day to day lives of people living with the disease will ensure that health care providers and programs provide relevant and beneficial care to a growing population with arthritis. This information is also critical to facilitate integration of arthritis into broader chronic disease management strategies as well as health care services.

## 2.0 Background

Arthritis comes in many forms, with more than a hundred different types<sup>5</sup>. Osteoarthritis, a degenerative joint disease, is the most common type of arthritis affecting 10% of the population, especially older people<sup>6,7</sup>. Inflammatory arthritis is characterized by inflammation of tissues associated with joints. Rheumatoid arthritis, the most common form of inflammatory arthritis, is an autoimmune disease that can affect multiple organs of the body and is typically a progressive chronic illness<sup>14</sup>. The use of self-management strategies to manage the symptoms, and consequences of arthritis is recognized in the scientific literature and by health care providers. A variety of self-management strategies are often recommended for people with arthritis. Self-management strategies or activities are broadly defined as activities people engage in to promote health and/or manage a chronic condition<sup>15</sup>. These are often therapeutic activities taught, prescribed or recommended by health care providers in collaboration with people with arthritis. The aims of these strategies are to reduce pain and inflammation, reduce the risk of deformities, and improve function<sup>16</sup>. In previous research examining the use of self-management strategies in people with rheumatoid arthritis, the most commonly employed strategies were technical aids and rest. In other research, Taal et al.<sup>17</sup> identified the self-reported most common self-management methods as technical aids, joint protection, rest and home exercise.

Self-management extends beyond addressing the physical needs of people with arthritis. The pain, fatigue and disability associated with arthritis can cause daily stress. Previous research has identified psychological stressors related to living with arthritis such as loss of independence, isolation, and changes in work or financial situations<sup>18</sup>. Daily stress has a significant effect on the prediction of depression and decreased life satisfaction in older adults<sup>19</sup>. Self-management strategies also provide methods for dealing with such

stress. For example, a number of studies examining self-management strategies have reported use of meditation and prayer as part of spiritual and relaxation practices<sup>15</sup>.

Self-management approaches can be taught on a one to one basis or in groups by health care providers or, in some group programs, lay leaders. Self-management programs often focus on patient education and problem-solving skills with the underlying goal of improving self-efficacy, the confidence that one can carry out a behaviour to reach a desired goal<sup>20</sup>. Evaluation of self-management education programs has shown that programs improve patient knowledge<sup>21</sup>, self-efficacy<sup>21</sup>, self-management behaviours (e.g. exercise, rest)<sup>22-24</sup>, and psychological status<sup>21</sup>, and decrease disability<sup>25</sup>. The *Arthritis Self-Management Program (ASMP)*, by Lorig and colleagues, has been most frequently evaluated with positive outcomes<sup>26</sup>. More recently, the generic *Chronic Disease Self-Management Program* has become more widely accepted. This course addresses the day-to-day self-management of symptoms of chronic conditions, with a particular focus on improving self-efficacy, problem-solving, decision making and confidence building<sup>27</sup>.

While research exists quantifying the use of certain self-management strategies for arthritis, less is known about the broad range of strategies used to manage arthritis, how they are integrated into daily life, and the challenges that people face in maintaining use of these strategies. This report explores the impact of arthritis on the daily lives of people living with the disease and the strategies that people with arthritis use to cope with a chronic disease in the community.

### 3.0 Objectives

Our previous report “*An Overview of Developments in Comprehensive Interdisciplinary Models of Care for Arthritis: Provider and Patient Perspectives*”<sup>28</sup> described best practice models of care for arthritis. This report highlighted the structures and processes required in the health care system and community to ensure timely delivery of optimal arthritis care based on key informant interviews with health care providers, educators and administrators, and patients’ perspectives. We found that patients identified the importance of emotional support, shared-decision making between patients and health care providers and education on arthritis for the public, health care providers and patients. In this report, the focus will shift to the patients’ perspectives on living with arthritis and strategies used to manage a chronic disease in the community.

The specific objectives of this report are:

1. To describe the daily impact of arthritis on community dwelling adults with arthritis; and
2. To identify common strategies that patients with arthritis use to manage their condition in the community.

### 4.0 Methodology

A qualitative methodology was used for data collection. Semi-structured interviews were conducted following guidelines set out by Krueger<sup>29</sup>. Interview guides were developed based on a literature review of best practices in arthritis management and models of care for arthritis, as well as consultation with colleagues. Questions were open-ended

and nondirective to encourage participants to identify issues of importance to them. As the discussion progressed, the questions became more specific to issues of arthritis management, and probes were used to stimulate further discussion where necessary. Some questions were added to interviews based on themes that emerged in previous interviews. Interviews were audio-taped and transcribed verbatim.

Interviews were conducted by two research associates with experience in qualitative research, one with a background in physiotherapy and the other in health promotion. At the beginning of the interview, the interviewer emphasized the confidential nature of the discussion. Consent forms were signed by participants prior to the interview. This study received ethics approval from the University Health Network Research Ethics Board.

## 4.1 Recruitment

Potential participants were recruited through the following sources:

1. The Arthritis Society staff in Ontario,
2. Postings with consumer groups,
3. Postings at a rheumatology clinic at Toronto Western Hospital and various primary care physicians' clinics, and
4. Postings (events, flyers, and newsletters) through The Arthritis Society.

Potential participants contacted the research associates through a toll-free telephone number to express interest in participating in the study. A telephone script was used to describe the study and to determine eligibility for admission to the study based on the inclusion criteria. Participants were required to meet the following eligibility requirements:

- A diagnosis of arthritis from a physician,
- Aged 18 years or older,
- Able to participate in a one hour interview,
- A resident of Ontario, and
- Able to understand and converse in English.

## 4.2 Analysis

Data were analyzed using a constant comparative approach<sup>30</sup>. A coding scheme was developed using an iterative, inductive approach. Two research associates performed initial open-coding of the interviews. Codes were compared and contrasted to develop a finalized coding scheme. Once a satisfactory level of agreement was reached, two research associates coded each transcript, using this coding scheme. They subsequently met to review the coding to ensure consistency in the definitions and interpretations of codes. The coded transcript data was entered into NUD\*IST Version 6 (N6), a data software program designed to assist with management of qualitative data. The data were then examined for common themes within and among each interview.

## 5.0 Results

### 5.1 Participant Description

Nineteen individuals with arthritis participated in this study. Participants ranged in age from 33 to 76 years, with a mean age of 56 years. They were predominantly female (89%) with higher education (trades certificate, diploma or post secondary education). Most participants lived with other family members, including a spouse and/or children, or parents. Five participants (26%) reported living alone. Participants reported various types of arthritis, most commonly inflammatory arthritis (rheumatoid arthritis and psoriatic arthritis) followed by osteoarthritis. The participants had limited disability with a mean score of 0.7, as measured by the Degree of Difficulty Subscale of the Modified Health Assessment Questionnaire<sup>31</sup>. The mean score is reported on eight items, (score 0-3), with a lower score representing less difficulty. These descriptive characteristics are consistent with community-based samples of other studies. Table 1 describes the participant characteristics and demographic information.

Table 1. Characteristics of Participants

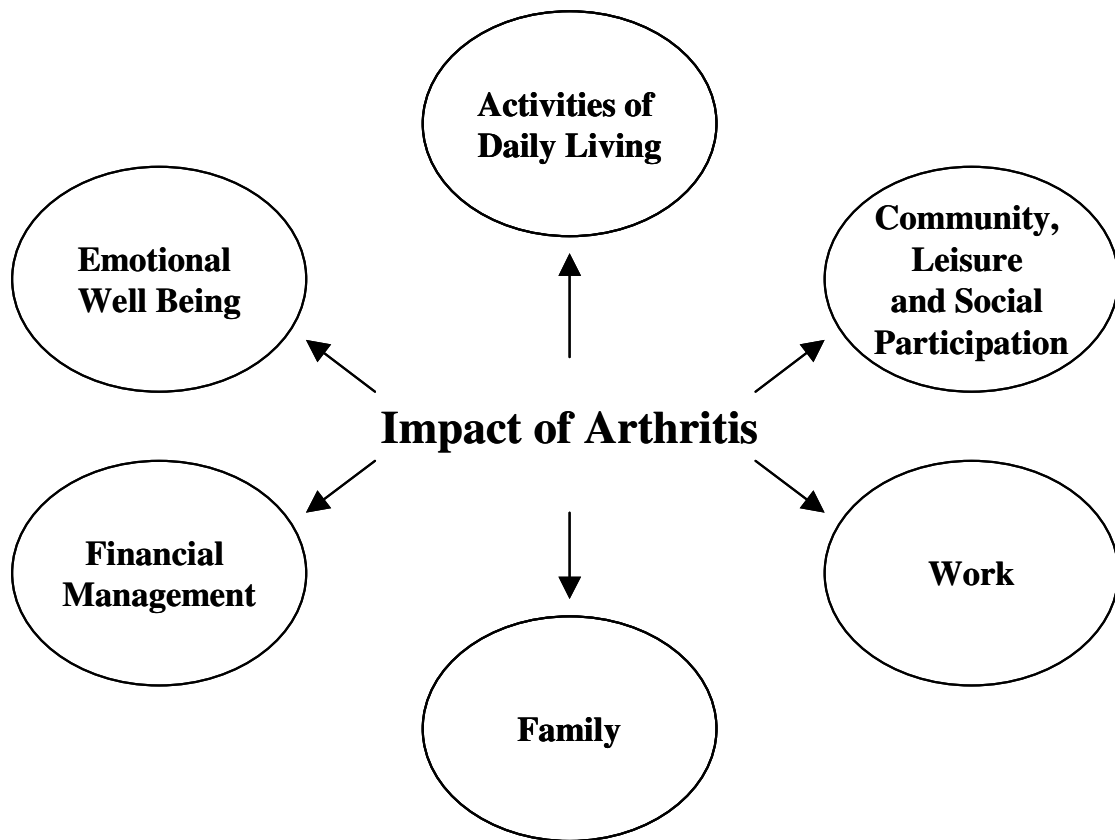
<b>DEMOGRAPHIC VARIABLES (n=19)</b>	<b>N</b>
Age, mean $\pm$ SD years	55.8 $\pm$ 10.9
Gender	
Female	17
Male	2
Education	
Secondary School or less	7
Trades certificate/diploma	2
Post Secondary	10
Living Arrangements	
Alone	5
With spouse	5
With spouse & children	5
With children	2
With parents	2
<b>ILLNESS RELATED VARIABLES (n=19)</b>	
Arthritis Type	
Rheumatoid Arthritis	4
Rheumatoid Arthritis + 1 or more other arthritis types	5
Osteoarthritis	5
Osteoarthritis + 1 or more other arthritis types	4
Psoriatic Arthritis	1
Duration, mean $\pm$ SD years	10.5 (7.6)
Co-morbid chronic conditions	
Yes	9
No	10
MHAQ Degree of Difficulty Subscale, mean $\pm$ SD	0.7 $\pm$ 0.4



## 5.2 Impact of Arthritis

Participants described the impact of living with arthritis on their daily lives throughout the course of their disease. Most participants identified that living with arthritis had a broad impact on all aspects of their life. Participants described changes in body functions and structures resulting from the disease that are commonly reported in other studies such as pain, stiffness, loss of strength and fatigue. The impact of the disease ranged from limitations in mobility and self care to restrictions in participation in work, family and social roles. From the interviews, six themes emerged to describe the impact of arthritis on people's lives. These are depicted in Figure 1.

Figure 1. Categories of life affected by arthritis



### Activities of Daily Living

Activities of daily living are often thought of as the things we normally do in daily living, including self-care and domestic activities. For the purposes of this report, we have also included mobility in the activities of daily living theme. Participants described the impact of arthritis on their self-care, mobility and domestic life activities. The impairments of the disease were commonly reported including pain, fatigue, swelling, loss of range of motion, stiffness and lack of strength. Pain in the joints is a particularly common feature of arthritis especially in the knees, hips, hands and feet. A report on arthritis in Ontario, showed that the proportion of people reporting pain that limits activities was greater for people reporting arthritis compared to other chronic conditions<sup>4</sup>.

Participants described the impact that arthritis had on their physical abilities to walk, climb stairs, lift and carry objects which is a direct consequence of the impairment and pain caused by the disease. Daily activities, such as personal care (e.g. dressing) and household chores (e.g. meal preparation), were often limited by the disease. All of this affected the ability of participants to be independent in carrying out their daily activities. The intermittent nature of the disease meant that these limitations were variable and difficult to predict. Unexpected flare ups of the disease were reported to be quite debilitating and to result in progressive physical changes (e.g. decreased range of motion and deformities in the joints) and loss of function. Table 2 displays common examples of challenges identified by participants in activities of daily living.

Table 2. Example of Challenges to Activities of Daily Living

Self Care	Mobility	Domestic Life
<ul style="list-style-type: none"> <li>• Getting in and out of bathtubs</li> <li>• Dressing (e.g. fastening buttons)</li> <li>• Cutting up food to eat</li> </ul>	<ul style="list-style-type: none"> <li>• Walking</li> <li>• Climbing stairs</li> <li>• Lifting</li> <li>• Carrying heavy objects</li> <li>• Getting out of a chair</li> <li>• Driving</li> <li>• Getting in and out of cars</li> </ul>	<ul style="list-style-type: none"> <li>• Household cleaning (e.g. vacuuming)</li> <li>• Yard work</li> <li>• Meal preparation</li> <li>• Opening jars</li> <li>• Opening taps</li> </ul>

These limitations in mobility and activities of daily living are well recognized as being affected in people with arthritis as reflected in the abundance of validated questionnaires and research in this area. Other research has shown that people reporting needing help with daily activities was greater for people reporting arthritis compared to other chronic conditions<sup>4</sup>.

### Community, Leisure and Social Participation

Many participants described how their social and community life had been affected by arthritis. Again, the variability and unpredictability of the disease was referred to as a challenge to social participation. In some cases, physical limitations in mobility restricted participants' ability to attend events outside their homes. Lack of accessibility in the community was reported as a limitation to socialization and leisure, including challenges with public transportation and parking as illustrated by one participant.

*There's a new library ... which I have not been to because I don't know where the parking is and that is the first question before I go anywhere, where's the parking?*

Most participants described that they had either modified or given up some of their leisure activities. These included sporting activities such as skating, swimming, basketball, baseball, skiing and dancing. Other recreational activities such as gardening, handcrafts, painting, playing cards, and renovation projects around the house were also reported as a challenge. As the level of disability increased, some participants

reported avoiding activities they really enjoyed because of the pain, fatigue and lack of energy associated with arthritis. The following quotes illustrate these challenges:

*Oh, I used to love swimming and now it's such a bother to get a bathing suit on...then it hurts to pull your arms past in the water so it's not the same pleasure with swimming so I wear a life jacket now...*

*...my hobby is painting and I am finding that I'm having difficulty painting and also too I have been having trouble reading because my neck has been bothering me and those are two activities that I really enjoy and, I don't want to, I find I am sort of avoiding them because of the pain...*

Some younger participants described the loss of friends who just could not relate to them after the onset of arthritis. However, several participants referred to meeting new friends who also have arthritis and understand the impact of the disease on their lives. Volunteering was identified as an important role for many participants, including arthritis related and community programs. Volunteering had replaced work for some participants forced to give up paid work due to the disease.

The challenges that participants in our study described related to community, leisure and social participation are not unique to this study. Gignac found that participants with osteoarthritis reported that a range of important activities and roles were affected by their condition. Among the most frequently mentioned were leisure activities, social activities, and community mobility<sup>32</sup>. Again, the physical symptoms of pain, stiffness and swelling that commonly affect the joints of the hands and wrist as well as lower extremity may have particular impact on leisure activities in people with arthritis compared to other chronic diseases.

## **Family**

Arthritis not only affects the person with the disease, but also has a significant impact on family members. Family was very important to participants and played an integral role in helping them to manage their arthritis. Many participants described how they were reliant on family for assistance to cope with their disease. This support they described was physical, emotional and financial in nature. Family members were reported to take on greater roles in terms of day-to-day household chores such as cooking, grocery shopping, laundry, and vacuuming, particularly during flare ups of the disease. When needed, they were also called upon to help with self-care (e.g. dressing).

Family members were reported to have a role in providing emotional support and often acted as sounding boards. Despite the fact that family members often struggle with coping with the changes in their loved one, it was noted by some participants that little attention is paid to formal emotional support for family members. One participant's experience depicts this challenge for family members. She described how the arthritis affected her marriage.

*I know my husband... I think it was harder for him than it was for me. At least it was happening to me and, you know, he should have been able to do something about that. And he could not. And he was, you know, the doctors were not communicating to him or anything and it was just, he did not know what to do...it was so frustrating and agonizing to go through that.*

Irrespective of the importance participants placed on family support, there was also a sense that there were times that family members did not understand the impact of the disease and could not always relate to how it feels to live with arthritis. The variability and invisible nature of the disease meant that family did not always recognize when the person with arthritis had pain and needed help. Some participants sought peer support to fill this gap.

For some participants, family was a source of financial support. Partners were sometimes thrust into the role of sole breadwinner when the person with arthritis was unable to work or is working on a reduced income. One participant described how she had moved in with her parents after being diagnosed as a young adult in order to cope with the challenges of the disease. For her, there was a sense that she should be helping her parents as they aged rather than receiving their support.

Participants with children recognized the impact that their arthritis had on their children. This included restrictions in activity such as not being able to have friends over to the house or having a parent who is unable to play with them. These parents described the impact of this on their children's development and the children's sense of responsibility in the family. One woman spoke of her young son who was very independent at an early age:

*I remember one time traveling, just the three of us and on the way home, I said to him, how come you never fall asleep in the car like you do when Daddy is with us. He said, because I know you are too sick to bring me into the house by yourself, pick [me] up out of the car.*

It is likely that some of these challenges related to family roles and relationships may be common to living with a chronic disease. Dealing with relationships with significant others is a common topic taught in self-management programs across chronic diseases<sup>27</sup>. There has also been research directed at education for families in order to promote disease management. Researchers have suggested that including family in management can be a promising adjunct to traditional care since this approach emphasizes the context in which the disease occurs, including the family's physical environment; educational, relational, and personal needs of patients and family members; and the ability to include the patients and family members in comprehensive programmes of care and outcome assessment<sup>33</sup>. Our study also highlights the need for support directed at families to meet their emotional health needs.

## **Work**

Work is another major life area that participants identified when discussing the impact of arthritis on their lives. Most participants identified that they reduced their working hours, changed their work environment and/or completely left their jobs. Many participants who completely left the work force often reported that they received disability benefits (e.g. Long Term Disability or Canada Pension Plan). The financial stress of not working or having a reduced income was particularly notable for people who were sole income earner for their household. A few participants identified the challenge of balancing work life and home life while coping with the pain and fatigue of arthritis. The following quote depicts this challenge:

*I finally had to give up working after my daughter was born because I realized that in order to be a mother at all to my children, I could not work, because I have so little energy. I love nursing. I had to give nursing up.*

It was evident from many participants that work is a feature of one's identity and that the loss of this role in their lives had significant emotional consequences beyond the financial stresses. Several participants reported that they wanted to return to work. Others recognized they would never participate in work again, which brought with it a sense of loss. The following participant's comments reflect the emotional challenges related to loss of work expressed by a number of participants:

*Well, it ended my teaching career. I think emotionally it was devastating. It is devastating, because you make plans for a life and they're changed totally... Loss of job is the big one (challenge). Sort of that whole issue of who you are, defined by what you do. So, if you can't do it anymore... So, it's to find again, who am I? I'm not a teacher anymore.*

Similarly, in other research, Backman<sup>34</sup> found that paid employment is necessary for economic self-sufficiency, and all forms of work, including child care and volunteer work, contribute to a person's sense of productivity and self-worth.

Participants who were not employed perceived there was a stigma associated with being unable to work and with receiving financial assistance. They noted that others perceived they were not productive members of society. For a few younger participants who hoped to return to work, there was also concern about challenges in re-entering the work force due to the gap on their resume when arthritis had resulted in being out of work for periods of time.

Participants who were employed reported concerns over a lack of understanding of arthritis by employers and colleagues. A few participants reported unwillingness to disclose their disease to employers for fear of losing a job. Having a supportive work environment (employer and co-workers) was suggested to increase an individual's likelihood of remaining employed. Participants also identified that flexibility to work modified hours or work at home was a factor in people with arthritis remaining employed, as was not having to commute to work.

There is an abundance of other research that has linked arthritis to loss of employment<sup>35-46</sup>. Another ACREU study of arthritis and employment examined arthritis-related workplace changes, including occasional work loss and changes to the type and hours of work. The results of this study found that seventy percent of respondents made at least one work change<sup>47</sup>. This same study examined the coping and self-management efforts used to manage arthritis and work and found that workplace activity limitations were related to increased reports of all types of coping. Women, those with more joints affected, and people expecting to remain employed reported more anticipatory coping strategies, or activities to help avoid problems such as planning and pacing. Expectations of continued employment, longer disease duration and discussing arthritis with one's employer were also related to modifications of activities at work<sup>48</sup>. Adapting to work has been identified as a common task in self-management across chronic diseases<sup>27</sup>.

## Financial Management

Most participants experienced a financial impact due to their arthritis. Participants with inflammatory arthritis reported considerable financial issues. Much of this stress related to the impact of arthritis on employment as described above. However, of significant note, are the additional costs associated with managing arthritis including:

- Medications
- Private health services such as physiotherapy, occupational therapy, massage therapy, optometry
- Assistive devices and orthopaedic shoes
- Community resources such as pool programs and exercise classes
- Parking expenses to attend health appointments
- Paid help around the house
- Renovations to the house

Many participants reported gaps in coverage between publicly funded services and services covered by private health insurance companies. Some participants admitted that they would limit access to services to make their coverage go further, or would not access services at all due to the cost. The costs of medications, in particular for inflammatory arthritis, accounted for significant proportions of family expenses. Here is one participant's example of out of pocket health care costs incurred at a time when the participant was experiencing pain and functional limitations due to arthritis:

*In 2004, I used, I spent over \$1500 out of my own pocket (for physiotherapy), plus the \$1000 [of insurance coverage] and I didn't have the money, but I still owe it, I'm still paying it off because I couldn't walk.*

In sum, changes in employment are only one aspect of the economic burden of arthritis. Out of pocket expenses incurred by people to self-manage chronic disease need to be further evaluated and considered as part of coping with a chronic disease.

## Emotional Well Being

The emotional impact of arthritis emerged as an important theme. It was evident that the emotional impact of the disease was as significant to participants as the physical challenges. Participants described a range of emotions as a result of their disease. Emotions included feelings of devastation, denial, anger and being overwhelmed in the early stages following their diagnosis as well as stress and worry as a result of financial, work and family pressures as the disease progressed. The unpredictability and variability of the disease contributed to the emotional stress for some participants as did concern about their future health. Fear of the future consequences of the disease included concern about loss of mobility, loss of independence, lack of control, costs and access to medications and services, and side effects of medications. Depression was also identified as being related to living with a chronic disease. A few participants identified feelings of shame related to the need to ask for help and financial assistance. Some of these emotions experienced by participants are reflected in the following examples:

*It was so frightening, I just, I was so afraid all the time. I was afraid of everything. I was afraid I would get into a situation I could not handle physically.*

*I'm also a little bit depressed. I'm not a depressive person, but when I'm so tired I can't even think or I can't even put a sentence together, it makes me feel I'm useless.*

### **Loss and change**

Much of the emotional impact of the disease included dealing with loss and change. Many participants referred to loss of independence or increasing dependence on others. They alluded to a loss of identity associated with these changes, particularly in reference to work. Participants described the challenges of coping with physical changes to their bodies, and losses in their mobility, activities of daily living and participation in leisure and social activities. All these in turn affect one's self-image.

*Basically, my life as I knew it ended and totally changed....I think the emotional devastation is much worse than the physical... You know it's all the 'can't's'. And [going] ... from a very independent person...to dependence. [Asking] "Can you do that for me?" It's tough, you know...*

### **Process of Acceptance**

Part of living with arthritis is accepting it as a chronic disease and acknowledging it is not going to go away. Many participants discussed acceptance as an ongoing process of adapting to the fact they were living with a chronic condition. This often included periods of denial in which participants acknowledged instances when they didn't want to believe they had arthritis or, in the case of younger participants, believing they were too young to have arthritis. As a result, some participants reported that they had not accepted health care, failed to modify activities or pace themselves. Feelings of denial and acceptance cycled throughout the disease trajectory.

Signs of acceptance of arthritis as a chronic disease were identified as accepting help from family; adopting self-management strategies and taking control of the disease; and acknowledging the pain but recognizing that there are good days and bad days. Here is one participant's illustration of acceptance:

*So, I think by and large it's acceptance. Now, it's a game, in a sense, to find, okay, I've got a problem, I can't do it this way, so let's find another way. So, it's adaptation...I guess what's changed is I am determined not to let this disease control my life which it originally did.*

### **Perception of disease**

As discussed in the 2006 report <sup>28</sup>, most participants felt that arthritis is a misunderstood disease and that, overall, there is a lack of understanding and awareness of arthritis by the public and, in some cases, health care providers. This challenge appeared to be an added source of stress to people coping with the disease. Participants reported that this misperception of arthritis affected attitudes at work, in the community, and even relationships with family and friends who didn't understand the need for adaptive strategies such as planning and pacing activities. Participants felt that people often couldn't appreciate the variability and invisible nature of the disease. The quote below illustrates the comments described by many participants:

*You know what the biggest problem is with the disease? You can't see it. It's a chronic disease and you can't see it and...the disease itself won't kill you...People are always...oh, you're getting old and you have to expect to have some aches and pains. Just the normal part of living.*

Coping with feelings such as anger, fear, and frustration is common to all chronic diseases<sup>22</sup>. Depression is more common in patients with rheumatoid arthritis than in healthy individuals<sup>49</sup>. Depression has also been found to occur as a comorbid condition in other chronic diseases such as diabetes<sup>50</sup>.

### **5.3 Arthritis Management Strategies**

Evidence-based best practices for the management of osteoarthritis and rheumatoid arthritis are well documented. They include exercise, self-management, medications, education, joint protection and assistive devices (Refer to ACREU Working "Report Care for People with Arthritis: Evidence and Best Practices"<sup>51</sup>). There is evidence to support the effectiveness of such interventions and strategies, including ample research on the effectiveness of self-management programs for arthritis and other chronic diseases. Despite this, less is known about what strategies people with arthritis use on a daily basis to manage their condition and how these strategies are adapted to their daily lives. In this study participants identified a variety of strategies they used to manage their arthritis. These strategies can be grouped into the following most common management methods:

- Information and Education
- Activity and Behaviour Modifications
- Environmental Changes
- Exercise
- Assistive Devices and Aids
- Orthoses
- Nutrition
- Conventional Medications
- Topical Treatments
- Alternative and Complementary Care
- Social Support and Positive Thinking

Table 3 provides examples to illustrate the types of self-management strategies used by participants in the study.



Table 3. Selected Examples of Self-Management Strategies

Strategy	Selected Examples
Education and information seeking	Seeking information on arthritis, community resources, medications and side-effects of medications
Activity and Behaviour Modifications	Giving up leisure activities such as swimming, running, knitting or sewing Planning meal preparation and errands ahead of time Detailed planning of travel itinerary before traveling Breaking up/reducing the time spent on activities such as cooking, housework, gardening Resting during the day Not wearing high heel shoes Getting assistance from family with dressing, household chores, lifting or carrying objects, or doing errands (e.g. grocery shopping) Hiring paid help with housework
Environmental Changes	Raising height of chairs and sofas to make it easier to get in/out Choosing to live in one storey home Purchasing a car to accommodate physical needs
Exercise	Walking, swimming, biking, skiing, golfing, yoga, tai chi Working with a personal trainer
Assistive devices and Aids	Aids to open jars and door knobs Foam extenders for handles or bigger grips for golf clubs Electric can openers and electric toothbrushes Canes and walkers Grab bars in the bathroom Reachers Handicap parking sticker Lighter dishes
Orthoses	Orthotics Wrist splints Knee braces Orthopaedic shoes
Nutrition	Eating a healthy diet Losing weight independently and through formal weight loss programs
Conventional Medications	Using medications such as: -Non-steroidal anti-inflammatory drugs (NSAIDs) -Disease Modifying Anti-Rheumatic drugs (DMARDs) -Cortizone injections -Over the counter medications (e.g. Tylenol)
Topical Treatments	Heat Ice Wax treatments Topical creams and ointments (e.g. Mynard's Linament)
Alternative and Complementary Care	Acupuncture Massage Herbal remedies
Social support and positive thinking	Support from family and friends Volunteerism in the community (e.g The Arthritis Society Arthritis Self-Management Program, school programs) Participation in support groups and religious groups Positive attitude Journals "Living in the moment"

## Information and Education

Most participants referred to the importance of education in effectively managing arthritis. Participants often sought information to learn more about the disease and how to manage it and to identify community and other resources. People identified needing information in order to make informed decisions. A common example of information needed to facilitate decision-making was in relation to weighing the risks and benefits of medication use with potential side effects.

## Activity and Behaviour Modifications

Participants developed self-management approaches to adapt to life with arthritis through planning and pacing of activities and seeking help from others. Many of the approaches that emerged from their narratives are recommended strategies for joint protection and energy conservation. Some participants described how they limit or modify recreation and leisure activities, work and household tasks. In some instances activities were given up completely. Often household activities, errands and even travel required more planning ahead of time. One participant described the detailed preparation she did to organize each step of a trip overseas to ensure that her physical limitations would be accommodated.

*Last year, I did go to England by myself and it took me 6 years to plan and prepare...I worked with a travel agent who made certain I had a wheelchair assist if I needed it...In airports, I had the golf carts that were laid on by the travel agent so that I could get to and from the gates.*

One participant described a daily example of planning ahead:

*You certainly plan ahead that you're not going up and down the stairs so often because it takes so long.*

Participants often indicated that getting informal help from family or friends for some activities was another key to managing with arthritis. It was noted that asking for help was often difficult for people, particularly in the early stages of the disease. Some participants used formal help for daily activities in the form of paid house cleaning.

Related to planning is pacing of activities. This refers to regulating the rate of activity. Many participants identified shortening the period of time spent on activities or breaking activities into shorter, more manageable tasks. For example, one participant described her strategy for completing the housework:

*So, I can take care of my house, but I do it in a very unique fashion, like 20 minutes of work, 20 minutes of rest...*

Participants gave testimonials of the challenge of pacing activities despite knowing that it was an effective strategy. One participant described failing to pace herself or "doing too much" as a reality check. The consequences of these actions were often a subsequent flare up of symptoms. Another participant noted:

*The hardest thing that I've had to do is pace. Everyone talks about pace your activities. In the real world it's really hard to do that.*

## **Environmental Changes**

Modifications were made to participants' environments to improve ease of mobility. These modifications included raising the height of furniture (putting risers in sofa); making everything accessible on one floor of house (renovations); and purchasing vehicles that were easy to get in and out of.

## **Exercise**

Exercise was frequently reported both in association with formal rehabilitation as prescribed by a physiotherapist and as self-directed exercise. Participants often acknowledged exercise as a beneficial component of self-management, but many referred to the challenge of maintaining an exercise program. One participant explained the process of building up strength through exercise only to have a flare up of the disease. She described losing the gains she'd made and starting from scratch again as being like "a board game where you keep going back to the beginning again".

The most common form of exercise identified was walking. A number of participants identified pool programs (e.g. aquafit) as key to management since the exercise could be performed with reduced pain and stress on joints. However, participants identified barriers in access to pool programs due to costs, location or timing of the classes.

## **Assistive Devices and Aids**

Assistive devices are defined as equipment, tools or products that are used to increase, maintain or improve functional capabilities of people with disabilities. Participants described several examples of assistive devices. The assistive devices described by participants included examples of both medical and everyday assistive devices.<sup>52</sup> Everyday devices are those devices that people use that were newly introduced by them or adapted by them in order to manage their condition<sup>52</sup>. One example of this was using an electric tooth brush to make it easier to perform the task. Medical assistive devices are designed for people with disabilities and available through suppliers. Examples of these are gait aids such as canes and walkers. One participant provided another example when she explained how a unique garden tool allowed her to maintain her hobby of gardening:

*So you're using the upper arm, there's no force going through the wrist and hand.*

## **Orthoses**

Braces and splints were common examples of physical appliances used to support and protect joints. Orthotics were also commonly used to relieve lower extremity symptoms and improve mobility.

## **Nutrition**

A number of participants identified the importance of eating a healthy diet as part of their overall health strategy. One participant related the importance of nutrition and nutritional supplements to her suppressed immune system:

*Because my immune system is so suppressed with all of these drugs. So it's calcium...and Actonel and things that'll develop the bone structure because ... my bone loss has been a problem with me.*

Others, more often those with osteoarthritis, discussed the importance of weight management for them to improve their function and pain. One participant reported the use of Jenny Craig to support weight loss. Another participant remarked:

*...I try to keep my weight down ...I note when I do take weight off you know you take 10 or 15 pounds off, it makes a difference. And when I, for instance, if I pick something up to carry around the house that is about 10 or 15 pounds and I notice it, you know, immediately the effect on your knees.*

### **Conventional Medication**

It was not surprising that all participants used medications, prescription or over the counter, to manage pain and slow disease progression. Yet, medication use, side effects, and decisions around medications, such as weighing the risks and benefits, were stresses mentioned by a number of participants. One participant described concerns with medications in the following quote:

*The side effects...is what I find a pain in the butt. What I don't like about medication is...I don't think there are enough long term studies being done on them...what happens after taking some of these drugs for 10-15 years? What's going on inside me?*

### **Topical Treatments**

The most common modalities used by people with arthritis in this study were heat and ice. A few participants also identified wax treatments and lotions and ointments as part of their self-management.

### **Alternative and Complementary Care**

Although most of the treatments used by participants of this study would be considered conventional medical care, a few participants discussed more natural and herbal remedies. Glucosamine, which has some evidence to support symptomatic relief of osteoarthritis and may also slow cartilage degeneration<sup>53-55</sup>, had been used by a number of participants. A few participants also referred to use of acupuncture for pain management. A number of participants were skeptical of the effectiveness of alternative and complementary care and were uncomfortable with using these treatments.

### **Social Support and Positive Thinking**

As previously reported, friends and family provide important emotional support. However, some participants felt that family and friends, despite being empathic, do not understand in the same way that other people living with arthritis do. Peer support was important to participants, especially early in the disease process. Remaining as active in the community as possible and volunteerism were important coping mechanisms for many people. Some participants volunteered with arthritis-specific groups, such as the arthritis self-management programs, which led them to build a social network that provided informal support and a source of information on arthritis resources. This is illustrated through a quote by one participant who said:

*As far as dealing and coping with it, I think it's having...knowing a lot of people with arthritis through the volunteer work, we have a lot of open discussions and a lot of people understand and it's people who've gone through whatever, and can give you advice.*

Support groups were important to some participants; however not everyone felt the need for formal groups. In some instances, health care providers also provided emotional support, including social workers and mental health services. Even the act of attending appointments reduced isolation and provided opportunity to meet others living with arthritis. Participants referred to the telephone as a strategy to communicate with family and friends to maintain social contact when it was difficult to socialize outside their homes.

Other sources of support were religion and religious groups. A few participants identified their religious community as important in providing both social and emotional support.

Finally, having a positive attitude to coping with arthritis was a common theme that emerged throughout the interviews. This was illustrated through participants' narratives of arthritis as a frequently episodic and unpredictable disease. A generally positive attitude to healthy lifestyle was often viewed as part of a broader approach to staying healthy. One participant stated it this way:

*...But the most important thing is to be positive and keep going, keep on trucking.*

## **5.4 Health Care and Community Services/Resources**

Health care services and community resources were often described as part of disease management. Participants' health care utilization, use of community resources and experiences with the health care system are described in detail in a separate report<sup>28</sup>. In summary, all participants reported contact with a primary care physician; most reported currently seeing or having seen a physiotherapist (n=17) and rheumatologist (n=14); and approximately half had seen an occupational therapist, and orthopaedic surgeon. For most participants with inflammatory arthritis, the rheumatologist was a key person in their care. However, one participant who reported a diagnosis of rheumatoid arthritis, had never received care by a rheumatologist. Almost half of participants had contact with other care providers such as chiropractors, massage therapists, reflexologists, naturopaths and acupuncturists.

The community resources described by participants fell into two categories:

- 1) General programs not designed for arthritis (may be specific to seniors)
- 2) Arthritis specific programs

Not all participants identified using community resources to manage arthritis. Common examples included pool programs, exercise classes and The Arthritis Society.

## **6.0 Discussion**

The results of our interviews suggest that arthritis has an impact on all aspects of one's life. The pain, fatigue and disability reported by people with arthritis affects activities of daily living such as mobility, housework and personal care, as well as participation in work, family, and social roles. Although the impact of arthritis on pain, function, and activities of daily living is well documented, the effect of arthritis on participation in major life areas such as family, work, and community life is less well understood and requires further research. The financial and emotional stresses reported in this study presented challenges equal to the physical challenges for many participants. These findings are

similar to those found in other research and suggest that care for people with arthritis must extend beyond physical disease management and include emotional support.

The self-management strategies reported in this study included a wide range of coping mechanisms and adaptations, including activity and behaviour modifications, exercise, assistive devices and aids, nutrition, medications and social support to name a few. Participants reported using a number of strategies at one time to control the disease. In some cases, participants reported that they knew some self-management strategies were important but reported challenges in maintaining the use of strategies. Pacing and exercise are two examples of these strategies that emerged from participants' narratives. Other quantitative research has found that for certain strategies namely joint protection and exercise, there was a discrepancy between believing in methods and doing them<sup>16</sup>. Some of this may relate to stages of change theory<sup>56</sup> among arthritis patients or to the ease of learning and subsequently implementing the strategies as suggested by other research<sup>16</sup>. Since educational-behavioural teaching methods have been shown to increase use of self-management strategies<sup>17;57</sup>, it is possible that for more complex strategies, support from health care providers or formal programs may increase uptake of the strategies.

With movement towards a chronic disease management approach, it is important to consider what factors are unique to arthritis and what commonalities arthritis has with other chronic diseases. Corbin and Strauss delineate three sets of tasks faced by people with chronic conditions:

- a) Medical management (e.g. taking medications, changing diet);
- b) Creating and maintaining new meaningful life roles (e.g. work, family and friends); and
- c) Coping with anger, fear, frustration and sadness of having a chronic condition<sup>58</sup>.

As evidenced by the current study, these tasks are relevant for individuals with arthritis. The specific medical management of arthritis requires consultation with health care providers in the health care system and/or arthritis education programs to meet the specific needs of people with arthritis. When examining the broad impact of arthritis, it is likely that the pain and physical challenges of arthritis affect activities of daily living, including self-care and mobility, and community, leisure and social participation in ways that may be unique to arthritis. Evidence-based self-management strategies for arthritis, such as medications, specific exercise, activity and behaviour modifications that promote joint protection, and assistive devices require arthritis specific interventions. Although some strategies, such as joint protection and exercise, can be taught by health care providers, not all education and support need be embedded within the health care system. In addition to the self-management programs that teach skills and promote self efficacy, other resources are important in promoting disease management in the community such as exercise groups, pool programs and social support.

There is a new paradigm of health care provider patient partnerships, in which patients are their own principal caregiver and the health care providers are consultants who provide support to individuals with chronic disease, including patient education<sup>59</sup>. In this role, health care providers provide information and assist patients in their own self-management<sup>60</sup>. It is key that health care providers are aware of resources outside the health care system, such as peer support, self-management/education programs and community programs that may assist people to self-manage their condition. Currently,

mechanisms to help health care providers remain aware of resources in the local community are lacking.

Other areas of life, such as family, finances, work and emotional well-being are likely to be similarly affected with other chronic diseases. This relates to Corbin and Strauss' second and third tasks. Self-management strategies such as social and emotional support, dealing with employers, and a healthy lifestyle (diet and general exercise) may have significant cross over with other chronic diseases. A review of self-management approaches for chronic diseases identified the main components of self-management programs across diseases<sup>22</sup>. Similar to our findings, this review found that information, drug and symptom management, management of psychological consequences, lifestyle (including exercise and diet), social support and communication were the major components. Those strategies that focused on symptom and pharmacological management were often disease-specific, while those that focused on approaches to manage the psychological consequences, social support and communication were generic skills to be applied in a disease-specific context. Arthritis and diabetes programs tended to be multi-component and targeted both knowledge and symptom management as well as generic skills<sup>22</sup>.

The narratives of many participants in this study indicate that having peers that understand the unique impact of arthritis, such as the variability and unpredictability of the disease, is crucial. Resources in the community for disease-specific support groups may be warranted.

Participants had a mix of rheumatoid arthritis and osteoarthritis in this study. Rheumatoid arthritis has traditionally been considered a more severe disease but the comparative data suggest the prevalence of impact is similar in the two patient populations<sup>61</sup>. This study also showed the disease groups had similar experiences related to the impact of arthritis.

## 7.0 Conclusion

The organization and development of models of care for chronic diseases such as arthritis is an ongoing challenge. Early diagnosis and referral to specialists is critical for people with inflammatory arthritis given the development of new medications that have the capacity to reduce some of the signs and symptoms of the disease and decrease joint destruction, particularly when initiated in the early stages of the disease<sup>62-73</sup>. Reducing waiting times for total joint replacement, a well accepted procedure shown to be effective in advanced arthritis, is currently a focus of governments working to improve access to care. Health care provider shortages are an ongoing challenge in the face of a growing population with arthritis necessitating new ways of delivering care for chronic disease<sup>4,74-76</sup>. Our previous report highlighted different models of care that have evolved to meet different needs: ensuring quality of care for arthritis or improving access to care in areas where waiting times and health care provider shortages have been a challenge<sup>28;51</sup>. These models tend to focus on care delivery within the health care system. Since much of "health care" is self-care in the community, an integral component of a model of chronic disease management is integration of health services, education and advice to support and empower people to manage their disease on a daily basis. Further research is needed to examine how disease-specific self-management strategies can best be integrated into broader chronic disease

management, whilst ensuring that people living with the disease receive the information and peer support they need.



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