Rheumatoid Arthritis: Balancing Activity and Rest

Lynn A. Lowe
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RHEUMATOID ARTHRITIS: BALANCING ACTIVITY AND REST

by

Lynn A. Lowe

A Thesis
Submitted to the
Faculty of The Graduate College
in partial fulfillment of the
requirements for the
Degree of Master of Science
Department of Occupational Therapy

Western Michigan University
Kalamazoo, Michigan
December 1987
Fatigue is a major symptom of rheumatoid arthritis (RA), along with joint pain, stiffness and functional impairment. Balancing activity and rest in order to decrease fatigue is frequently mentioned by health professionals as an important strategy in the management of the disease. One hundred and three adult men and women with RA were surveyed via a written questionnaire about their experience of fatigue, four types of rest, employment status, duration of illness, age, sex, and advice about rest. Frequencies related to these variables are reported. Some rest variables were found to be significantly correlated with age and fatigue. No significant correlations were found between fatigue and age or duration of illness. Significant differences in rest variables were found when comparing groups that differed in duration of illness, sex or employment status. No significant differences in fatigue were found in a comparison of men and women.
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Rheumatoid arthritis: Balancing activity and rest

Lowe, Lynn A., M.S.
Western Michigan University, 1987

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CHAPTER I

STATEMENT OF THE PROBLEM

Rheumatoid arthritis (RA) is a systemic disease which causes inflammation of the joints, joint pain, stiffness, functional impairment, and fatigue. According to the literature, RA patients who obtain sufficient rest to prevent fatigue may show improvements in other symptoms of the disease.

The concept of balancing activity and rest is an integral part of joint protection and energy conservation principles used to treat RA patients in occupational therapy (Cordery, 1965; Melvin, 1982; Pedretti, 1985; Trombly, 1983). Little research has been done on the frequency and qualitative aspects of fatigue in RA, and the benefits of specific types and amounts of rest for RA patients.

Several questions are raised about fatigue and patterns of rest in RA patients. What is the frequency of fatigue in RA patients and how do they perceive fatigue? Do they incorporate rest into their daily routine, and if so, what types and amounts of rest do they achieve? What is the relationship between fatigue and rest? How do RA patients learn about the role of rest in the management of the disease and what advice are they given by health professionals? How do factors such as sex, age, employment and duration of illness affect fatigue and rest in RA patients?
CHAPTER II

LITERATURE REVIEW

The experience of fatigue and patterns of rest in RA patients were examined in this study. The role of factors such as sex, age, employment, and duration of illness, on the experience of fatigue and patterns of rest in RA patients was also examined, as well as advice about rest from health professionals. This section reviews the general characteristics of the disease; fatigue in RA; recommendations concerning rest for RA patients; the concept of balancing activity and rest; patient education about rest; and the role of occupational therapists in the treatment of RA patients.

General Characteristics of Rheumatoid Arthritis

Rheumatoid arthritis is a chronic, systemic, inflammatory disease that affects the soft connective tissue and is characterized by unpredictable periods of exacerbation and remission (Strodthoff, 1982). Due to its chronic course and potentially crippling effects, the disease is an important medical and social problem (Urbanek, Sitajova, & Hudakova, 1984). As many as three percent of the adult population have RA, which equals nearly 7 million people in the United States (Arthritis Foundation, 1984). It affects 7% of the elderly population over age 75 (McDuffie, 1985). Since the prevalence rate of RA increases with age, the disease will become more
common as the proportion of elderly individuals in the population grows (Meenan, Epstein, Nevitt, & Yelin, 1981).

Symptoms of the disease include fatigue, stiffness, pain, weakness, and joint inflammation (Lansbury, 1968). The disease may change a person's physical appearance and disrupt routine activities. Consequently, attitudinal changes and psychological reactions such as fear, depression, panic, denial, dependency, and poor self-image, may occur.

Fatigue

Fatigue is a prominent symptom of RA. It is considered to be a reliable index of rheumatoid arthritis activity and is used as a guide to therapy (Lansbury, 1968; Smith & Polley, 1978). Although the terms "fatigue" and "tiredness" were used frequently and interchangeably in the literature reviewed, there appeared to be no operational definitions, even in research studies. Sugarman and Berg (1984) pointed out that patients seeking treatment from a general practitioner "may use the term fatigue to denote experiences as diverse as the need for excessive sleep, the inability to satisfactorily perform physical tasks compared with previous ability, or a pervasive sense of lethargy" (p. 643).

"Fatigue" and/or "tiredness" have been reported by large percentages of RA patients surveyed on this subject. Smith and Polley (1978) cited a study done by Short, Bauer, and Reynolds, who found that "weakness and fatigue" occurred in 80% of 293 RA patients surveyed, and that it was less common in men. Brighton and Louw
(1981) found that "tiredness" was reported to be mild in 36% of 100 patients surveyed, moderate in 38% and severe in 25% of patients. Wright and Owen (1976) found that in their interviews of 37 homemakers with RA, all were distressed about their "tiredness and the general limitation of activities" (p. 157).

Little has been written about the measurement of fatigue in RA patients. Lansbury, Baier, and McCracken (1962) described their measure of fatigue as "subjective" and elicited it by interviewing the patient. They reported that description of fatigue had more interobserver reliability than morning stiffness. Furst et al. (1987) measured fatigue by a visual analogue scale, which they added to the Stanford Health Assessment Questionnaire. These authors also had subjects rate their fatigue on a four point scale during each half-hour period of an activity log over a forty-eight hour period. A definition of fatigue was not given in either of these studies.

Several characteristics of fatigue in RA patients were described in the literature. Smith and Polley (1978) stated that patients with RA generally sleep well and are rested when they awaken, but describe fatigue occurring sometimes abruptly and early in the day at a consistent time of day. This phenomenon of early fatigue was documented in a study by Brighton and Louw (1981). These authors surveyed 100 RA patients and found that many of them experienced "afternoon tiredness." Another reported characteristic of RA fatigue is that it puts a tremendous drain on the person's psychological as well as physical resources (Lorig & Fries, 1980;
Melvin, 1982). Also stated in the literature is that other symptoms of the disease may increase during periods of fatigue (Kielhofner, 1986; Smith & Polley, 1978).

Fatigue is a symptom that cannot be seen and thus is often misunderstood by friends, family, and co-workers of the RA patient. It may be misinterpreted as a sign of laziness or malingering. The results can be conflicts between others' expectations and what one can actually do (Kielhofner, 1986; Lorig & Fries, 1980; Rogers, Liang & Partridge, 1982). Cordery (1965) stated that among arthritics who continue to work, their most flagrant neglect is the conservation of their personal physical resources. RA patients may not obtain sufficient rest during the working day because they fear for their employment if their co-workers see them resting (Cordery, 1965; Rogers et al., 1982). A patient who works may have little energy for other activities (Lorig & Fries, 1980; Rogers et al., 1982).

Homemakers interviewed by Wright and Owen (1976) stated that they exhausted themselves in household duties to the extent they were unable to get out and participate in activities outside the home. Kielhofner (1986) pointed out that persons with physical disabilities may be torn between their belief that time should be used productively and the medically dictated necessity of rest. The concept of resting for a few minutes in the middle of a household chore, such as vacuuming, is totally foreign to the majority of homemakers. The desire to get housework done and "over with" is usually a strong one (Melvin, 1982). The consequence is that the
patient may become fatigued and have little energy for other activities.

Rest

The concept of rest for RA patients was not consistently defined in the literature. For the purpose of this study, rest was defined as a physical withdrawal from activity by sleeping, lying down without sleeping, or sitting. This definition was created to include four types of rest for RA patients recommended in the literature: (1) nighttime sleep, (2) daytime sleep, (3) lying down without sleeping (hereafter also referred to as "lying down rest"), and (4) sitting for short rest periods. While the literature included both general and specific recommendations for each type of rest, few studies have documented the benefits of specific amounts of types of rest.

The RA patient's need for at least ten hours of rest at night and/or one to two hours of rest in the afternoon is frequently mentioned in the literature (Cordery, 1965; Decker, 1978; Halpern, 1984; Mayne, 1973; Melvin, 1982; Strodthoff, 1982). Furst et al. (1987) recommended two daily one hour rest periods, to be taken lying down. Brighton and Louw (1981) recommended a one-half to one hour lying down rest period to be taken during the lunch break. While many authors recommend rest lying down during the day, most do not specify that it is necessary for the patient to sleep. Mayne (1973) stated that the patient should truly withdraw from physical and mental activity. He specified that "sedentary activities, such
as reading or watching television, are inadequate substitutes for bedrest" (p. 93).

Short rest breaks taken sitting down are another type of rest frequently recommended by health professionals. Van Deusen and Harlowe (1987) defined rest in their Exercise-Rest Self-Report Scales as "I am able to sit quietly and rest my joints." Furst et al. (1987) recommended that 10 minute rest breaks be taken during activities that take 30 minutes or longer to complete. Pedretti (1985) stated that "5 to 10 minutes of rest to 30 or 40 minutes of activity is adequate" (p. 299). Halpern (1984) recommended 10 minute rest breaks every hour throughout the day. Melvin (1982), Furst et al. (1987), and Lorig and Fries (1980) each stated that taking a 5 to 10 minute break during activities can significantly increase endurance. Short periods of rest are helpful even when the patient does not complain of fatigue (Decker, 1978).

Most the studies of the benefits of rest for RA patients were from the literature of health professions other than occupational therapy and were done in hospital settings. Mills (1971) and Alexander, Hortas and Bacon (1983) studied the effects of prolonged bed rest (19-22 hours per day) on hospitalized RA patients. Lee, Kennedy, Anderson and Buchanan (1974) studied the effects of hospitalization treatment program with a minimum of 13 hours per day bed rest. Gault and Spyker (1969) studied the effects of resting a specific joint by immobilizing the joint in a plaster cast.

Recent literature indicates that techniques which may be considered as forms of rest, such as relaxation exercises, stress
management training, and biofeedback are being recommended as ways to control pain and stress in RA patients (Johnson & Repp, 1984; Lorig & Fries, 1980). Some studies have been done to document the effectiveness of these techniques in RA patients. Shearn and Fireman (1985) studied the effects of a stress management group and a mutual support group on functional disability and disease activity in RA patients. The only significant difference between patients in the intervention group was an improvement in joint tenderness when compared to the control group. No significant differences were found in pain, morning stiffness, or self-rated functional disability. In a study by Achterberg, McGraw, and Lawlis (1984), relaxation and temperature biofeedback training were shown to have a significant, positive effect on physical/functional indices in RA patients, when compared with a traditional physiotherapy group.

The prescription of adequate rest in RA produces a difficult therapeutic challenge (Smith & Polley, 1978). The amount of rest varies with the individual patient, depending on the stage of the disease, activity tolerance, and any special systemic or joint problems that affect the performance (Arthritis Foundation, 1984; Pedretti, 1985). No studies have been done to document the types and amounts of rest RA patients actually achieve. The relationship between a patient's pattern of rest and factors such as sex, age, duration of illness and employment have not been explored in the literature.
The Concept of Balancing Activity and Rest

Balancing activity and rest is frequently mentioned as one of the main components of joint protection and energy conservation in occupational therapy. Cordery (1965) stated that "finding the point of balance of activity and rest is basic to the control of symptoms both systemically in the patient and locally in a joint" (p. 285). Melvin (1982) stressed that the use of rest during the day's activities is "probably the most effective weapon a person with arthritis can use against the demands of the disease" (p. 353). Pedretti (1985) stated that the occupational therapist should help the RA patient work out a daily schedule of intermittent rest and activity.

Furst et al. (1987) studied the effects of the National Institutes for Health Energy Conservation Program on energy conservation behaviors of 28 RA patients. These authors developed a formula for computing, in effect, the RA patient's balance of activity and rest. The index of physical activity (IPA) was based on the frequency of rest periods of any length, divided by the total number of half-hours of physical activity, and multiplied by 100. Three months after the program, experimental subjects showed improvements in rest during physical activity, balance between rest and activity (IPA) and time spent physically active, although these improvements were not statistically significant. Both experimental and control groups showed decreased pain and fatigue.

The prescription of balancing activity and rest is also in the literature of health professionals other than occupational thera-
pists involved in the treatment of RA patients (Chamberlain, 1984; Halpern, 1984; Hench et al., 1935; Johnson & Repp, 1984; St. Clair & Polisson, 1986). Smith and Polley (1978) stated that RA patients who obtain sufficient rest to prevent fatigue show greater improvement and seem to require less medication. Balancing activity and rest has also been said to be an important strategy in decreasing joint pain and inflammation (Arthritis Foundation, 1983; Johnson & Repp, 1984).

Patient Education

Information on balancing activity and rest is provided to RA patients by health professionals, patient support and education groups, and written materials. Smith and Polley (1978) stated that the importance of rest is usually accepted by patients only after it has been stressed repeatedly by their physician. Few studies have examined RA patient compliance with advice about rest. Most compliance studies have focused on compliance with medication or exercise regimes.

The Arthritis Foundation, a national voluntary organization, provides educational programs and written materials to arthritis patients and their families through regional and local chapters. The Arthritis Self-Help Course, offered by many of the local chapters, includes information on energy conservation, rest, and pacing activities. Their brochures and written materials also stress the importance of rest in managing the disease (Arthritis Foundation, 1983; 1984).
Studies that have been done on patient education groups show mixed effects on the RA patient's use of rest. Some studies have shown that patient education groups such as the Arthritis Foundation Self-Help Course significantly increase the use of rest and/or relaxation techniques (Lorig, 1981; Lorig, Lubeck, Kraines, Seleznick, & Holman, 1984). Other studies have shown that the effects of patient education groups do not significantly increase these behaviors (Cohen, Sauter, Devellis & Devellis, 1982; Furst et al., 1987; Van Deusen & Harlowe, 1987)

The Role of Occupational Therapy in the Treatment of RA Patients

"Occupational therapy (OT) is an important part of the team approach to total health care for the arthritis patient" (Halpern, 1984). Occupational therapy services for the RA patient focus on assessment of and training in activities of daily living, patient education regarding the disease, principles of joint protection and energy conservation, and post-operative upper extremity rehabilitation (Kales-Rogoff, 1979). Joint protection and energy conservation are important principles utilized to treat the RA patient in occupational therapy (Cordery, 1965; Kales-Rogoff, 1979; Melvin, 1982; Pedretti, 1985; Trombly, 1983).

A study of fatigue and patterns of rest in RA patients can be an important addition to occupational therapy literature. It can be valuable to find out about how RA patients experience fatigue, the types and amounts of rest they achieve, and if they do so with the advice of health professionals. This information can help occupa-
tional therapists understand how fatigue in RA affects a person's daily routine of activities. Comparing rest patterns of groups differing in age, duration of illness, sex, and employment status can lead to better understanding of how these factors may affect an RA patient's need for rest. Occupational therapists can use this knowledge to assist RA patients in planning a daily routine that incorporates an effective amount and type of rest that is compatible with his/her lifestyle. The findings may also have implications for other chronic illnesses where fatigue is a major symptom and a balance of activity and rest is recommended and/or prescribed.
CHAPTER III

HYPOTHESES

This study was designed to investigate: (a) the frequency and qualitative aspects of fatigue among RA patients, (b) the frequency and type of advice given by health professionals to RA patients about rest, (c) the type and amount of rest achieved by RA patients, and (d) additional behaviors and attitudes related to balancing activity and rest.

In addition, the following null hypotheses about RA patients were tested in three major areas:

Relevant to fatigue:

1. There are significant correlations
   a) between fatigue and age
   b) between fatigue and duration of illness.

2. There is no significant difference in fatigue between men and women.

Relevant to four types of rest (nighttime sleep, daytime sleep, lying down rest, and sitting for short breaks):

3. There are no significant differences in types of rest between men and women.

4. There are no significant differences in types of rest between the following groups:
   a) employed vs. non-employed
b) homemakers vs. non-homemakers

c) retired vs. non-retired

5. There are no significant correlations
   a) between types of rest and age
   b) between types of rest and duration of illness

Relevant to comparing fatigue and rest:

6. There are no significant correlations between fatigue and
   the four types of rest.
CHAPTER IV

METHOD

Subjects

Subjects were 23 male and 80 female adults who reported being diagnosed as having rheumatoid arthritis. The proposal for this study was approved by the Human Subjects Institutional Review Board at Western Michigan University. Two pools of subjects (N = 103) were surveyed via a written questionnaire. The first pool consisted of 15 subjects who contacted the researcher about participating in the study as a result of announcements in the newsletter of a local branch of the Michigan Arthritis Foundation. The researcher mailed the questionnaire directly to these subjects. One hundred seventy nine questionnaires were mailed to three local rheumatology offices and six offices of the Arthritis Foundation in six different cities in Michigan. These offices volunteered to distribute the questionnaires to their patients and members. The 88 persons who returned the questionnaires made up the second pool of subjects.

Instrumentation

The questionnaire (see Appendix for a copy of the questionnaire) was developed with a primarily close-ended format for its simplicity of completion and ease of analysis (Dillman, 1978; Rossi, Wright & Anderson, 1983). A few open-ended questions were included

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to obtain information that could not be elicited by close-ended questions. Each mailing included an addressed stamped envelope in which to return the questionnaire. A follow-up postcard was sent to subjects in the first pool exactly one week after the initial mailing of the questionnaire, as suggested by Dillman (1978). This postcard reminded subjects to complete and return the questionnaire. A follow-up postcard was sent to the agencies to remind them to distribute the questionnaires.

Data Analysis

Data was analyzed on the Dec-1099 computer at Western Michigan University using the SPSS Package for Condescriptive, Frequency, Crosstabs, Chi-square, Eta, Pearson product-moment and Spearman rho statistics (Nie, Hull, Jenkins, Steinbrenner & Bent, 1975; Norusis, 1982).
CHAPTER V

RESULTS

Demographics

Fifty-four percent of 196 questionnaires distributed were returned. Three questionnaires were not included in the data analysis because of inappropriate diagnosis or age of the respondents. Results are based on 103 questionnaires.

Ages of the respondents ranged from 23 to 78 years, with an average age of 53; 78% were female and 22% were male; 98% of the subjects indicated that they had been diagnosed with RA; the other 2% indicated a diagnosis of Juvenile Rheumatoid Arthritis. Duration of the illness ranged from two months to 49 years, with a mean duration of 12 years. Ninety percent indicated that they were taking medication for RA.

Thirty-six percent of the respondents indicated that they were employed; 43% reported being homemakers; 29% were retired and 11% were unemployed.

Results pertinent to the null hypotheses will be reported under the next three subsections: fatigue, rest, and relationship between fatigue and rest.

Fatigue

Respondents were surveyed on several aspects of their expe-
rience of fatigue. When asked to check one or more statements that describe their experience of fatigue, 57% checked "lack of ability to do physical tasks"; 50% checked "excessive need for rest" and 44% described it as a "feeling of lethargy." Several respondents wrote in additional descriptions such as mental fatigue or tiredness. Fifty-four percent reported that other RA symptoms are worse during periods of fatigue.

In response to the question about when fatigue occurs during the day, 60% reported that their fatigue tends to occur around a consistent time of day. Of those indicating that fatigue occurs at a consistent time of day, 63% reported fatigue occurring in the afternoon; 15% in the morning; 15% in the evening, and 8% reporting both morning and evening.

Thirty-two percent of the respondents reported that they believed medical conditions other than RA might cause them to experience fatigue. A comparison between these respondents and those that did not report additional fatiguing conditions, however, revealed no significant differences in the days per week of experiencing fatigue ($X^2 = 4.17976, p = .9943$).

Respondents were asked how many days per week they experienced fatigue. Fifty-eight percent of those answering the question ($N = 94$) reported fatigue occurring five or more days per week, with 40% reporting fatigue on a daily basis. Five percent indicated that they did not experience fatigue. Table 1 shows the distribution of days per week of fatigue according to sex, three categories of age (20 to 40 years; 41 to 60 years; and 61 to 80 years) and two
categories of duration of illness (less than or equal to 12 years; and greater than 12 years).

Table 1

Days Per Week of Experiencing Fatigue According to Categories of Sex, Age and Duration of Illness

<table>
<thead>
<tr>
<th>Days per week*</th>
<th>N</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Sex</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Men</td>
<td>9.5</td>
<td>0.0</td>
</tr>
<tr>
<td>Women</td>
<td>4.1</td>
<td>4.1</td>
</tr>
<tr>
<td><strong>Age</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>20-40 yrs.</td>
<td>11.1</td>
<td>0.0</td>
</tr>
<tr>
<td>41-60 yrs.</td>
<td>3.4</td>
<td>5.1</td>
</tr>
<tr>
<td>61-80 yrs.</td>
<td>5.9</td>
<td>0.0</td>
</tr>
<tr>
<td><strong>Duration</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>of Illness</td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt; 12 yrs.</td>
<td>6.8</td>
<td>1.7</td>
</tr>
<tr>
<td>&gt; 12 yrs.</td>
<td>2.9</td>
<td>5.9</td>
</tr>
</tbody>
</table>

* Data are reported in percent of responses for each category under days per week. Percents were calculated by dividing the N at the right into the number of respondents who gave that response.

While only thirty-five percent of the women and over half (57%) of the men reported experiencing fatigue on a daily basis, a Chi-square analysis revealed that the difference was not significant.
No significant differences in fatigue between the three categories of age or between the two categories of duration of illness. No significant correlations were found by computing age and duration of illness as interval level data, and comparing them to fatigue, using the Pearson product-moment statistic. As a result of these findings, the first two null hypotheses could not be rejected.

Rest

Respondents were surveyed about four types of rest: nighttime sleep, daytime sleep, lying down rest and short breaks taken sitting down. Table 2 shows the distribution of daily rest measured in hours per day of nighttime sleep, daytime sleep and lying down rest, as reported by respondents. Nighttime sleep ranged from five or fewer hours to twelve hours daily, with an average of 7.5 hours. It is interesting to note that nighttime sleep did not correlate significantly with any of the other rest variables, or with fatigue, age, or duration of illness. No significant differences in nighttime sleep were found between the sexes or between groups differing in employment status.

Respondents were asked to report the number of days per week they slept during the day, and the number of hours per day. Responses ranged from zero to seven days per week, with 59% reporting at least one day per week of daytime sleep. Eight percent reported daytime sleep on a daily basis. The daily amount of daytime sleep ranged from zero to two hours. For those who slept
Table 2

Daily Rest: Hours Per Day of Nighttime Sleep, Daytime Sleep, and Lying Down Rest*

<table>
<thead>
<tr>
<th>Hours per night</th>
<th>5 (or less)</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
<th>11</th>
<th>12</th>
<th>no response</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nighttime Sleep</td>
<td>8.7</td>
<td>13.6</td>
<td>25.2</td>
<td>28.2</td>
<td>16.5</td>
<td>5.8</td>
<td>1.0</td>
<td>1.0</td>
<td>0.0</td>
</tr>
<tr>
<td>Hours per day</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>0 (or less)</td>
<td>41.2</td>
<td>20.5</td>
<td>22.5</td>
<td>8.8</td>
<td>6.9</td>
<td>0.0</td>
<td>0.0</td>
<td>0.0</td>
<td>1.0</td>
</tr>
<tr>
<td>Daytime Sleep</td>
<td></td>
<td>31.4</td>
<td>27.5</td>
<td>16.7</td>
<td>5.9</td>
<td>7.8</td>
<td>2.0</td>
<td>2.9</td>
<td>4.9</td>
</tr>
</tbody>
</table>

*Data is reported in percent of responses.

during the day at least one day per week, the average amount was approximately one hour. Using the Spearman rho statistic, a highly significant correlation was found between days per week and hours per day of daytime sleep (rho = .8578, p = .001).

Respondents were also asked about days per week and hours per day of lying down rest. Sixty-nine percent of respondents reported lying down rest at least one day per week, with 19 percent of respondents reporting lying down rest on a daily basis. The daily
amount of lying down rest ranged from zero to 3.5 hours per day. For the respondents reporting at least one hour per week of lying down rest, the average amount was approximately one hour and fifteen minutes. In comparing days per week and hours per day of lying down rest, a highly significant correlation was found (\( \rho = 0.8378, p = .001 \)).

Table 3 shows the frequency of the practice of taking breaks of 5 to 10 minutes sitting down and activities during which these rest breaks were taken. Fifty-two percent of the respondents reported

Table 3

<table>
<thead>
<tr>
<th>Frequency</th>
<th>Responses (%)</th>
<th>Responses (Actual #)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Several times per day</td>
<td>52.4</td>
<td>54</td>
</tr>
<tr>
<td>Once per day</td>
<td>8.7</td>
<td>9</td>
</tr>
<tr>
<td>Several times per week</td>
<td>21.4</td>
<td>22</td>
</tr>
<tr>
<td>Once per week</td>
<td>1.9</td>
<td>2</td>
</tr>
<tr>
<td>Hardly ever</td>
<td>12.6</td>
<td>13</td>
</tr>
<tr>
<td>No response</td>
<td>2.9</td>
<td>3</td>
</tr>
<tr>
<td><strong>100.0%</strong></td>
<td><strong>N=103</strong></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Activity</th>
<th>% of respondents</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td>Shopping at a mall</td>
<td>55.3</td>
<td>101</td>
</tr>
<tr>
<td>Laundry</td>
<td>37.9</td>
<td>102</td>
</tr>
<tr>
<td>Vacuuming</td>
<td>33.0</td>
<td>101</td>
</tr>
</tbody>
</table>
Table 3—Continued

<table>
<thead>
<tr>
<th>Activity</th>
<th>% of respondents</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td>Meal preparation</td>
<td>30.1</td>
<td>103</td>
</tr>
<tr>
<td>Going for a walk</td>
<td>22.3</td>
<td>101</td>
</tr>
<tr>
<td>Dressing</td>
<td>16.5</td>
<td>103</td>
</tr>
<tr>
<td>I do not usually take rest breaks</td>
<td></td>
<td></td>
</tr>
<tr>
<td>during any of these activities</td>
<td>15.5</td>
<td>103</td>
</tr>
</tbody>
</table>

that they take short rest breaks "several times per day"; 13% indicated that they "hardly ever" use this form of rest. Activities during which rest breaks were most frequently taken were shopping at a mall (55%), laundry (38%), and vacuuming (33%). Sixteen percent indicated that they did not take breaks during any of the six activities listed.

Table 4 shows the comparison of days per week of daytime sleep between the following groups: men vs. women, employed vs. non-employed, retired vs. non-retired, and homemakers vs. non-homemakers. A Chi-square analysis showed that men in the survey reported significantly more days per week of daytime sleep than did women ($X^2 = 18.2853, p = .0015$). This was the only significant difference in the rest variables between the sexes. On the basis of these findings, only one of the four types of rest (daytime sleep) in the third hypothesis can be rejected.

Significant differences in daytime sleep were found in two of the three comparisons of groups differing in employment status:
Table 4

Comparisons of Days Per Week of Daytime Sleep in Men and Women; Employed and Non-Employed; Homemaker and Non-Homemaker; and Retired and Non-Retired

<table>
<thead>
<tr>
<th>Days per week*</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>N Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Men</td>
<td>9.1</td>
<td>22.7</td>
<td>13.6</td>
<td>0.8</td>
<td>13.6</td>
<td>18.2</td>
<td>18.2</td>
<td>4.5</td>
<td>22</td>
</tr>
<tr>
<td>Women</td>
<td>38.8</td>
<td>3.8</td>
<td>18.8</td>
<td>8.8</td>
<td>11.3</td>
<td>6.3</td>
<td>3.8</td>
<td>8.8</td>
<td>88</td>
</tr>
<tr>
<td>Employed</td>
<td>51.4</td>
<td>13.5</td>
<td>13.5</td>
<td>5.4</td>
<td>8.1</td>
<td>2.7</td>
<td>5.4</td>
<td>0.0</td>
<td>37</td>
</tr>
<tr>
<td>Non-employed</td>
<td>20.3</td>
<td>4.7</td>
<td>20.3</td>
<td>7.8</td>
<td>14.1</td>
<td>12.5</td>
<td>7.8</td>
<td>12.5</td>
<td>64</td>
</tr>
<tr>
<td>Homemaker</td>
<td>31.8</td>
<td>4.5</td>
<td>20.5</td>
<td>13.6</td>
<td>11.4</td>
<td>9.1</td>
<td>2.3</td>
<td>6.8</td>
<td>44</td>
</tr>
<tr>
<td>Non-homemaker</td>
<td>32.8</td>
<td>10.3</td>
<td>15.5</td>
<td>1.7</td>
<td>12.1</td>
<td>8.6</td>
<td>10.3</td>
<td>8.6</td>
<td>58</td>
</tr>
<tr>
<td>Retired</td>
<td>13.8</td>
<td>6.9</td>
<td>20.7</td>
<td>6.9</td>
<td>17.2</td>
<td>13.8</td>
<td>6.9</td>
<td>13.8</td>
<td>29</td>
</tr>
<tr>
<td>Non-retired</td>
<td>39.7</td>
<td>8.2</td>
<td>16.4</td>
<td>6.8</td>
<td>9.6</td>
<td>6.8</td>
<td>6.8</td>
<td>5.5</td>
<td>73</td>
</tr>
</tbody>
</table>

* Data are reported in percent of responses for each category under days per week. Percents were calculated by dividing the N at the right into the number of respondents who gave that response.

employed versus non-employed and retired versus non-retired. Those employed reported significantly less daytime sleep than the non-employed, both in the number of hours per day and in the number of days per week ($\chi^2 = 19.83775$, $p = .0059$ and $\chi^2 = 23.28844$, $p = .0015$, respectively). This was the only rest variable that differed significantly in the employed vs. non-employed comparison, thus rejecting the null hypothesis under 4a, relative to daytime sleep, which is one of the four rest types. Those who were retired reported significantly more daytime sleep on a daily basis compared to non-retired respondents ($\chi^2 = 17.22697$, $p = .016$). Based on this finding, one of the four rest types (daytime sleep) in hypothesis 4b can be rejected. When comparing respondents who identified them-
selves as homemakers with those who did not, no significant differences were found in any of the rest variables, therefore hypothesis 4c cannot be rejected.

Table 5 shows the correlations with mild levels of association found between age and two of the rest variables: days per week of daytime sleep and days per week of lying down rest, using the Pearson product-moment statistic. Age was found to be significantly correlated with days per week of daytime sleep ($r = .3159, p = .0015$). A very mild significant inverse relationship was also found between age and days per week of lying down rest. A comparison of age with hours per day of daytime sleep, also showed a significant correlation, using the Spearman rho statistic ($\rho = .3073, p = .001$). Based on these findings, two of the four rest types (lying down rest and daytime sleep) compared to age in hypothesis 5a can be rejected.

Table 5 also shows the relationships between duration of illness and the same two rest variables, using the Pearson product-moment. Duration of illness as interval level data was not found to correlate with any of the rest variables, thus failing to reject hypothesis 5b. However, when comparing respondents with an RA duration of more than 12 years with those whose illness duration was 12 years or less, a Chi-square analysis showed significantly more days per week of daytime sleep in the group with the longer duration of illness ($X^2 = 14.90817, p = .04$).
Table 5

Correlations Between Experience of Fatigue, Weekly Patterns of Rest, Duration of Illness, and Age Using the Pearson Product-Moment Statistic

<table>
<thead>
<tr>
<th></th>
<th>Daytime sleep days/week</th>
<th>Lying down rest days/week</th>
<th>Duration of illness</th>
<th>Age</th>
</tr>
</thead>
<tbody>
<tr>
<td>Exp. fatigue days/week</td>
<td>r</td>
<td>.2491</td>
<td>.4428</td>
<td>.0872</td>
</tr>
<tr>
<td></td>
<td>N</td>
<td>94</td>
<td>92</td>
<td>93</td>
</tr>
<tr>
<td></td>
<td>p</td>
<td>.008*</td>
<td>.001*</td>
<td></td>
</tr>
<tr>
<td>Daytime sleep days/week</td>
<td>r</td>
<td>.2224</td>
<td>.1321</td>
<td>.3159</td>
</tr>
<tr>
<td></td>
<td>N</td>
<td>100</td>
<td>100</td>
<td>102</td>
</tr>
<tr>
<td></td>
<td>p</td>
<td>.013*</td>
<td>.095</td>
<td>.001*</td>
</tr>
<tr>
<td>Lying down rest days/</td>
<td>r</td>
<td></td>
<td>.0033</td>
<td>.1908</td>
</tr>
<tr>
<td>week</td>
<td>N</td>
<td></td>
<td>99</td>
<td>101</td>
</tr>
<tr>
<td></td>
<td>p</td>
<td></td>
<td>.487</td>
<td>.028*</td>
</tr>
<tr>
<td>Duration of illness</td>
<td>r</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age</td>
<td>N</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>p</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*p < .05 indicates significance

The Relationship Between Fatigue and Rest

Significant correlations with mild to moderate levels of association were found between fatigue and three of the four rest types (lying down rest, daytime sleep, and sitting for short breaks), therefore hypothesis 6 can be rejected. A Chi-square analysis revealed that those individuals who marked the statement "I do not experience fatigue," showed a significantly lower frequency of short rest breaks when compared with those who did experience fatigue (\(\chi^2 = 10.65854; p = .03\)).

Table 5 shows the significant correlations between fatigue and
daytime sleep and lying down rest, using the Pearson product-moment statistic \( (r = .2491, p = .008 \) and \( r = .4428, p = .0001 \), respectively). Using the Spearman rho, fatigue and the frequency taking of short rest breaks were also found to be significantly correlated (rho = .3065; \( p = .001 \)). Nighttime sleep was the only type of rest not found to be correlated with fatigue.

Advice, Behaviors, and Attitudes Related to Balancing Activity and Rest

Respondents were asked how they learned about the role of rest in the management of RA and given a checklist of several sources. Rheumatologists were the most frequently mentioned health professional (75%); others included family physicians (36%), physical therapists (32%) and occupational therapists (27%). Eight percent of respondents checked the statement "Have never been given any advice (about rest) by a health professional." Other sources of information about rest included brochures (52%), books (50%), others with RA (32%) and self-help groups (26%). Sixty-five percent of the respondents marked the statement "Figured it out on my own."

When asked in an open-ended question what advice they were given about rest from health professionals, a wide range of responses were given. "Rest when tired" or "as needed"; "get lots of rest" or "as much as possible" and "rest every day" were the most frequently mentioned types of advice. "Lie down every day" or "nap every day"; "take lots of short rest breaks" and "alternate light and heavy tasks" were also mentioned. Very few respondents reported receiving advice that specified a number of hours of day or night-
time rest. Respondents were asked if they followed the advice about rest given to them by health professionals. Fifty one percent indicated they did follow the advice; 32% did "some" and 3% did not follow the advice.

Table 6 shows the distribution of responses to a series of statements asking the respondents about their attitudes and behaviors related to balancing activity and rest. A majority (67%) of respondents appeared to perceive rest as beneficial by marking statements indicating that short rest breaks usually helped them to feel rested and that if they did not rest during the day, they would experience fatigue. Only 15% marked the statement indicating that they "felt fine" if they did not rest during the day. A majority of respondents indicated that they took a break in the middle of a heavy task (69%), planned ahead to organize their activities (74%) and managed their time so that they did not have to rush (67%).

A majority of respondents indicated that while they had enough energy to do their work, they sometimes would not have enough energy left over to do the things that they enjoyed. Forty one per cent of respondents indicated that they would sit down and take a break at work if they needed to, while only 12% indicated they would lie down and take a break at work if they needed to. In asking for help in getting tasks done during periods of fatigue, 36% indicated they would ask family members or friends. Only 13% indicated they would ask coworkers for help when fatigued.
<table>
<thead>
<tr>
<th>Frequency of Behaviors and Attitudes Related to Balancing Activity and Rest, as Marked by Respondents. All Data is Reported in Percents (N = 103)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Table 6</strong></td>
</tr>
<tr>
<td><strong>Usually</strong></td>
</tr>
<tr>
<td>1. Short rest breaks help me feel rested ........ 67.0</td>
</tr>
<tr>
<td>2. If I do not rest during the day, I experience fatigue .......... 67.0</td>
</tr>
<tr>
<td>3. I feel fine, even if I don't rest during the day .......... 15.5</td>
</tr>
<tr>
<td>4. I would feel better if I got more sleep ........ 32.0</td>
</tr>
<tr>
<td>5. I plan my day so that more active chores can be done when I am the least fatigued .......... 67.0</td>
</tr>
<tr>
<td>6. When I have a heavy task to do, I will stop in the middle of it and take a break ........ 68.9</td>
</tr>
<tr>
<td>7. I plan ahead, organizing my activities and combining errands so that it takes less effort to get everything done ........ 74.8</td>
</tr>
<tr>
<td>8. I manage my time so that I don't have to rush .. 68.0</td>
</tr>
<tr>
<td>9. I have enough energy to work, but not enough left over to do things that I enjoy .......... 25.2</td>
</tr>
<tr>
<td>10. I sit down and take a break at work if I need to rest 39.8</td>
</tr>
</tbody>
</table>

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<table>
<thead>
<tr>
<th></th>
<th>Usually</th>
<th>Sometimes</th>
<th>Rarely</th>
<th>Blank</th>
</tr>
</thead>
<tbody>
<tr>
<td>11. I lie down and take a break at work if I need to rest</td>
<td>11.7</td>
<td>9.7</td>
<td>44.7</td>
<td>34.0</td>
</tr>
<tr>
<td>12. I feel in control of the pace of my daily routine</td>
<td>58.3</td>
<td>30.1</td>
<td>8.7</td>
<td>2.9</td>
</tr>
<tr>
<td>13. When I am experiencing fatigue, I ask for help from family members or friends in getting tasks done</td>
<td>35.0</td>
<td>30.1</td>
<td>33.0</td>
<td>1.9</td>
</tr>
<tr>
<td>14. When I am experiencing fatigue, I ask for help from coworkers in getting tasks done</td>
<td>12.6</td>
<td>17.5</td>
<td>39.8</td>
<td>30.1</td>
</tr>
<tr>
<td>15. I rest before I experience fatigue</td>
<td>13.6</td>
<td>48.5</td>
<td>35.0</td>
<td>2.9</td>
</tr>
</tbody>
</table>
CHAPTER VI

DISCUSSION

This study had several limitations. First, it did not use a random sample. Subjects were recruited for the study by rheumatology offices and Arthritis Foundation chapters, and questionnaires were distributed to all who volunteered. Unfortunately, questionnaires were not coded to determine what percentage of returned questionnaires came from each source, and thus any significant differences between the two groups could not be identified. Another limitation is the type of information that can be obtained with a written questionnaire. This information is self-report in nature and there is no means of checking its reliability. Also on a written questionnaire, respondents may answer a question incorrectly or leave it blank, when they misinterpret it or find it confusing. Some questions had a no response rate as high as 34%.

The primarily close-ended format of the questionnaire resulted in much ordinal level data. More powerful statistics could have been used to analyze the data, had the questions been designed to obtain interval level data.

Fatigue

Results support the many statements in the literature that fatigue is a common symptom of RA. While most respondents indicated
that they experience fatigue, only 37% indicated that they experience it on a daily basis. This is new information about the nature of fatigue in RA. Authors such as Smith and Polley (1978) and Brighton and Louw (1981) indicated in their writings about fatigue that it tends to occur on a daily basis. These authors stated that fatigue often tends to occur at a consistent time of day. This study supports this idea, with 63% of respondents indicating that this was true for them. Of these respondents, a majority indicated that fatigue usually occurs in the afternoon, as was found by Brighton and Louw (1981). A small percentage reported fatigue occurring consistently in the morning or evening.

The finding that a majority of respondents indicated that other RA symptoms often seem to be worse during periods of fatigue supports statements made by Kielhofner (1986) and Smith and Polley (1978).

It is interesting to note that more men than women reported daily fatigue, even though the difference was not statistically significant. These findings refute a study by Short et al., cited by Smith and Polley (1978), who found that fatigue was less common in men. More data is needed in this area to better understand differences that may exist between the sexes in the experience of fatigue.

No significant correlations were found between fatigue and age or duration of illness. It may be that fatigue is a function of the severity of the illness, which may be a factor independent of sex, age, or duration of the illness.
One limitation of this study was that fatigue was not defined for the respondents, so that when respondents were asked how many days per week they experienced fatigue, the variety in responses could reflect the variety in personal definitions or experience of the word fatigue. The study showed that respondents did vary in their perceptions of fatigue, demonstrated by the mixed response to the three statements describing fatigue as a "lack of ability to do physical tasks" (57%), an excessive need for rest (50%), "a sense of lethargy" (44%).

Significant correlations were found between fatigue and three of the four types of rest, indicating that people who report a high frequency of fatigue tend to report greater amounts of daytime sleep, lying down rest, and short rest breaks taken sitting down. It is not clear from this study if these respondents rest more because their disease process is exacerbating and the severity of their symptoms are causing them to rest more, or if greater amounts of rest actually increase their feeling of fatigue. While the results of this study demonstrate a significant relationship between fatigue and rest, the practice of obtaining sufficient rest to avoid fatigue was not directly assessed in this study. Several authors have described the beneficial effects of this practice on the disease process (Arthritis Foundation, 1983; Johnson & Repp, 1984; Smith & Polley, 1978). However, only 14% of the respondents stated that they are in the habit of resting before experiencing fatigue.
Rest

Results indicate that while most respondents appeared to view rest as beneficial, a majority do not sleep 10 hours at night and/or lie down one to two hours during the day. Ten to twelve hours of rest at night and a one to two hour daytime rest period is frequently recommended in the literature (Cordery, 1965; Decker, 1978; Halpern, 1984). Only eight percent of respondents reported 10 hours or more sleep at night.

Thirty two percent of respondents reported that they did not sleep during the day. Of those that did sleep during the day, the average duration of the rest period was 59 minutes, which is close to the one to two hours recommended in the literature. Similarly, while 29% of the respondents indicated that they did not obtain lying down rest, of those that did, the average duration of this type of rest period was approximately one hour and fifteen minutes. A minority of respondents reported lying down rest one to two hours on a daily basis and even fewer reported daytime sleep seven days per week. Sitting for short rest breaks appeared to be the most consistent daily pattern of rest, with a majority of respondents reporting taking 5 to 10 minute rest breaks several times per day, as was frequently recommended in the literature (Decker, 1978; Furst et al., 1987; Lorig & Fries, 1980, Melvin, 1982; Pedretti, 1985).

Highly significant correlations were found between daily and weekly patterns of daytime rest. These correlations indicated that the number of hours per day a person lies down tends to increase with the number of days per week of daytime rest. Thus, the longer
the periods of rest, the more likely they are to rest during the day on a regular basis. Those who lie down for 15 minutes per day are more likely to do so only one or two days per week. This tendency was found to be true for daytime sleep, as well as for lying down rest.

Another interesting discovery was that men reported more days per week of daytime sleep than did women. A possible explanation is that women may have more household or parental responsibilities that may prevent them from sleeping during the day. The spouses of women with RA may be less willing or have less time to help them with these daytime responsibilities.

Although no significant correlations were found between fatigue and age, mild but highly significant correlations indicated that one form of rest, daytime sleep, tends to increase with age. No significant correlations were found between duration of illness and any of the four types of rest. However, significantly more daytime sleep was found in respondents with an illness duration of more than 12 years when compared to those with a lesser duration of RA.

Since the respondents with a greater duration of illness also tend to be older, it is possible that increased daytime sleep is more a function of the aging process rather than cumulative effects of a longer duration of the disease. The study also showed that those who were retired reported significantly more daytime sleep than those who were non-retired. A possible explanation is that those who are retired may have more time to sleep during the day. It is interesting to note that those respondents who were older
tended to rest more days per week than the younger respondents, but they did not report experiencing fatigue more days per week.

In contrast to the retired, those who were employed reported significantly less daytime sleep, both on a daily and weekly basis. A logical explanation is that if they are employed during the day, chances are they have less opportunity for daytime sleep. Another possibility is that if they feel good enough to work, their disease process may be such that they feel less of a need for daytime sleep.

A majority of those respondents answering questions about work in Table 6 indicated that they would usually sit down and take a break if they needed to rest at work. Substantially fewer respondents indicated that they would lie down to take a break. This may be because they do not feel the need to lie down. Another possibility is that they may not wish to be seen by their coworkers as resting, for fear they will be perceived as lazy or malingering, as suggested by Cordery (1965), Kielhofner (1986), and Lorig and Fries (1980). Another possible reason is that there may not be any facilities available for lying down at their place of employment.

It is also interesting to note that according to the responses in Table 6, respondents are more willing to ask for help from family members or friends rather than coworkers. One drawback in interpreting the responses to these questions about work is that those who were employed were not the only respondents to answer these questions.

It is interesting to note that homemakers did not differ significantly from non-homemakers in any of the four rest types.
One possible explanation is the variety in daily routines and responsibilities of those who identified themselves as homemakers. On the questionnaire, homemaker was not an exclusive category and thus some employed and retired respondents also identified themselves as homemakers.

The study showed that almost all of the respondents reported being given advice about rest by health professionals, and that most reported following the advice to some extent. When asked about what advice they were given, most answers were vague and consisted of one or two general statements. It is not known if this is the type of advice they originally received or if this is what they recall from the original advice. In addition to professional advice, the study showed that 65% of respondents reported learning about rest on their own and a majority of respondents also sought out written materials.

Implications for Occupational Therapists

This study has several implications for occupational therapists. It investigated the habits of RA patients and documented frequencies of several types of rest that are incorporated into the daily routines of RA patients. This study documented that a majority of RA patients perceive rest as beneficial and practice energy conservation behaviors related to balancing activity and rest. Occupational therapists need to understand the nature of fatigue in RA patients in order to assist them in balancing activity and rest. It is important for the occupational therapist to know that the following characteristics of fatigue in RA were reported to
be true for a majority of respondents: that they do experience fatigue, that other symptoms of RA may worsen during periods of fatigue, and that fatigue may tend to occur at a consistent time of day, and most often in the afternoon.

It is important for occupational therapists to gain an understanding of realistic types and amounts of rest for an RA patient. This study showed that sitting for short breaks was the type of rest most consistently practiced by respondents on a daily basis.

The knowledge that patterns of rest may be affected by age and employment status is also important for occupational therapists to consider. The findings that daytime sleep tends to increase with age and retirement can be used by occupational therapists working with the older RA patient.

Further Research

Since so few studies have been done related to fatigue and rest in RA, there are many possibilities for further research. It would be interesting to find out more about qualitative aspects of fatigue such as intensity (mild/moderate/severe), mental versus physical fatigue, and the relationship of fatigue to depression and motivation. It would be valuable to further examine the differences in fatigue and rest in groups that differ in age, sex, roles in the home and specific work environments. Severity of illness, level of physical activity, and medication are all factors that could be compared with fatigue and patterns of rest.
CHAPTER VII

CONCLUSION

There are many statements in the literature related to balancing activity and rest in RA patients, but few recommendations are grounded in research. This study investigated fatigue and four types of rest in RA patients, and their relationship to factors such as age, sex, duration of illness, and employment status. Significant relationships were found between fatigue and three of the four types of rest. Significant differences in types of rest were found in groups that differed in age, duration of illness, sex and employment status. These findings demonstrate the need for further research in this area.
RHEUMATOID ARTHRITIS: BALANCING ACTIVITY AND REST
QUESTIONNAIRE

This study is an attempt to find out how people with RA incorporate rest into their daily routine. You will be asked questions about your experience of fatigue, patterns of rest, and advice given to you by health professionals on these subjects.

PART A.

Many people with RA report that they experience fatigue. You may or may not experience this. Answer the questions as they apply to you.

1. Check any of the statements below that describe your experience of fatigue:
   ___Excessive need for rest
   ___Lack of ability to do physical tasks
   ___Feeling of lethargy
   ___I don't experience fatigue
   ___Other ___________________________________________

2. Circle the number of days in an average week that you experience fatigue:
   0 1 2 3 4 5 6 7

3. Does your fatigue tend to occur around the same time every day? ___YES ___NO
   (If no, please skip to #5.)

4. If yes, write in the time of day your fatigue usually occurs: ___________

5. Write in the words "MOST" and "LEAST" next to the times of day that you are most and least likely to experience fatigue:
   __Morning _____________ Afternoon _____________ Evening

6. Does fatigue affect any of your other RA symptoms? ___YES ___NO
   (If no, please skip to #8.)

7. How does fatigue affect your other RA symptoms? (check all that apply)
   ___RA symptoms are worse during fatigue
   ___RA symptoms are worse the next day
   ___RA symptoms are better during fatigue
   ___Other (explain) ___________________________________________

8. On days that you have to rush to get certain tasks completed, does rushing increase your level of fatigue? (check one of the responses below)
   ___Usually ___Sometimes ___Rarely
PART B.

In this section, you will be asked about three different kinds of rest: sleep, lying down without sleeping, and taking short rest breaks by sitting down. Answer these questions as they apply to you.

9. Circle the number of hours you usually SLEEP at night:
   (less than) 5 6 7 8 9 10 11 12 13 (or more)

10. Circle the total number of hours you usually SLEEP during the day:
    0 1/4 1/2 1 1 1/2 2 2 1/2 3 3 1/2 (or more)

11. Circle the number of days in an average week that you SLEEP during the days:
    0 1 2 3 4 5 6 7

12. Circle the number of hours in an average day that you rest LYING DOWN WITHOUT SLEEPING:
    0 1/4 1/2 1 1 1/2 2 2 1/2 3 3 1/2 (or more)

13. Circle the number of days in an average week that you rest LYING DOWN WITHOUT SLEEPING:
    0 1 2 3 4 5 6 7

14. Another way people with RA rest is to stop in the middle of an activity and sit down for a 5 to 10 minute break. Mark how often you use this form of rest: (check one of the following)
    ___hardly ever ___once a day
    ___once a week ___several times a day
    ___several times weekly

15. Mark any of the activities listed below where you usually take rest breaks:
    ___Meal preparation ___Getting dressed
    ___Shopping at a mall ___Going for a walk
    ___Vacuuming ___Other (list) ------------------
    ___Doing laundry ___I do not usually take breaks
during any of these activities

16. Fill in the blanks: Ideally, to feel rested, I need _____ hours of sleep at night and _____ hours of sleep during the day.

17. Fill in the blank: Ideally, to feel rested, I need _____ hours of lying down (without sleeping) during the day.
Please read the statements below and mark if they are "usually", "sometimes", or "rarely" true for you:

<table>
<thead>
<tr>
<th>Statement</th>
<th>Usually</th>
<th>Sometimes</th>
<th>Rarely</th>
</tr>
</thead>
<tbody>
<tr>
<td>18. Short rest breaks help me feel rested.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>19. If I do not rest during the day, I experience fatigue.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>20. I feel fine, even if I don't rest during the day.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>21. I would feel better if I got more sleep.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>22. I plan my day so that more active chores can be done when I am the least fatigued.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>23. When I have a heavy task to do, I will stop in the middle of it and take a break.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>24. I plan ahead, organizing my activities and combining errands so that it takes less effort to get everything done.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>25. I manage my time so that I don't have to rush.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>26. I have enough energy to work, but not enough left over to do things that I enjoy.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>27. I sit down and take a break at work if I need to rest.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>28. I lie down and take a break at work if I need to rest.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>29. I feel in control of the pace of my daily routine.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>30. When I am experiencing fatigue, I ask for help from family members or friends in getting tasks done.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>31. When I am experiencing fatigue, I ask for help from coworkers in getting tasks done.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>32. I rest before I experience fatigue.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>33. Please feel free to use the space below to make any additional comments about your experience of fatigue and/or rest, and the ways that you cope with your RA.</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
PART C.

This section will explore how you have learned about the role of rest in the management of RA.

34. Mark which health professionals, if any, have given you advice about rest. (check all that apply)

___Have never been given advice by a health professional
___Family physician
___Rheumatologist
___Occupational therapist
___Physical therapist
___Nurse
___Counselor
___Other___________________

35. What advice were you given about rest?________________________________________

36. Do you follow the advice? ___YES ___NO ___SOME (please explain)

37. How else have you learned about the role of rest in the management of RA?
(check all that apply)

___Figured it out on my own
___Books
___Time management class
___Stress management class
___Brochures
___Arthritis Self-help Group
___Other people with RA
___Other___________________

PART D.

Finally, I would like to ask you a few questions about yourself and your RA history to help interpret the results of this survey.

38. Your age: _____

39. Your sex: Female_____ Male_____

40. Work Status:

check all that apply  ___Employed  ___Student  ___Homemaker  ___Volunteer  ___Retired  ___Unemployed  ___Other

# hours per week

41. If employed, job title:__________________________________________

42. Duties:__________________________________________
43. Estimate how many hours in an average 24-hour day you spend sitting, on your feet, and lying down:

<table>
<thead>
<tr>
<th>Activity</th>
<th>Hours</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sitting</td>
<td>-----</td>
</tr>
<tr>
<td>On your feet</td>
<td>-----</td>
</tr>
<tr>
<td>Lying down</td>
<td>-----</td>
</tr>
</tbody>
</table>

44. Please check all that apply:

- I live alone
- I live with a parent(s)
- I live with a spouse
- I live with a friend(s)
- I live with one child
- I live with two or more children
- Other

45. Please indicate if you are responsible for doing the following activities for yourself and/or for others in your household. Also indicate if others help you with these activities. (Check all that apply)

<table>
<thead>
<tr>
<th>Activity</th>
<th>I do this for myself</th>
<th>I do this for others</th>
<th>Others help me with this</th>
</tr>
</thead>
<tbody>
<tr>
<td>Meal preparation</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>House cleaning</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yard work</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Shopping</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Transportation</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Personal care (dressing, bathing)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Household repairs/maintenance</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

MEDICAL INFORMATION:

46. Please indicate your diagnosis:

- Rheumatoid arthritis
- Juvenile rheumatoid arthritis
- Other

47. Approximate date of onset of arthritis symptoms: _______________

48. Approximate date of diagnosis: _______________

49. Are you currently on medication (including aspirin) for RA?  
   - YES  □ NO

50. Do you have medical conditions other than RA that may cause you to experience fatigue?  
    - YES  □ NO

If yes, please name: ________________________________

51. Please describe the severity of your RA: ____________________________


