PARTICIPATION IN PAID AND UNPAID WORK BY ADULTS WITH RHEUMATOID ARTHRITIS

by

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Abstract

This study explored factors associated with participation in paid and unpaid work by adults with rheumatoid arthritis (RA). Up to 50% of people with RA stop employment prematurely because of their illness. Performance of unpaid work, such as household work, home maintenance, care-giving, and volunteering, has been given little attention.

A cross-sectional mailed survey was designed in consultation with working age adults with RA. Participation in paid and unpaid work was defined as self-reported number of hours worked "last week." Test-retest reliability coefficients (ICC) for the measures of paid and unpaid work were .99 and .90. Concurrent validity, assessed using a 24-hour diary, was r = .96 for paid work and r = .75 for unpaid work. Potential explanatory factors, conceptually organized as attributes of the person, environment, or occupation, included health and functional status, social support, type of work and work demands.

Participants were recruited by written invitation from their rheumatologist (n = 239, 40% of those invited). They were 18 to 66 years old (mean = 50), had RA for an average of 13 years, and 81% were female. They reported an average of 47 hours of work in the week prior to survey date, 19 paid and 28 unpaid hours.

Using regression analyses, more hours of paid work were associated with psychologically demanding work, higher social function, less pain, being male, managerial job type, and lower ratings of occupational balance ($R^2 = .25$). More hours of unpaid work were associated with more children in the household, more physically and psychologically demanding work, social support from family, and having a post-secondary education ($R^2 = .43$). Satisfaction with work performance was associated with higher self-efficacy, greater occupational balance, more skill discretion in one's work, and smaller household size. Seventy-three participants were working less because of their arthritis. Lower functional status, more pain, less psychologically demanding work, and being a household worker were associated with this work limitation due to RA.

Study results may influence the content of rehabilitation and education programs aimed at helping people with RA maintain or return to productive occupations, by suggesting some functional and psychosocial factors linked to paid and unpaid work.

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Chapter I Literature Review

1.1 Introduction

Work represents a major life role for most adults. Paid employment is necessary for economic self-sufficiency, and all forms of work (including employment, household work, child care and volunteer work) contribute to a person's sense of productivity and self worth. Impairments resulting from chronic illness may limit people's ability to engage in daily occupations and valued activities. Participation in paid and unpaid work is viewed as a determinant of health because inability to engage in these productive activities may threaten an individual's economic, social, physical or mental well-being. In fact, recent revisions by the World Health Organization (WHO) to its classification system of impairments, disabilities and handicaps (ICIDH-2), have acknowledged "participation" in daily life activities appropriate to one's age, culture and community, as a major indicator of health status (WHO, 1999).

The ICIDH-2 is based on a model of functioning and disability that depicts several inter-relationships among body functions and structures, activity, participation, environmental factors, personal factors and health conditions. In this model, "activities" are the performance of a task or action and "participation" is an individual's involvement in life situations (WHO, 1999). Health conditions may restrict body functions, activities or participation. The extent to which a given condition may limit activities or participation also depends on personal factors (such as age or education) and environmental factors (like housing or community supports). The present thesis explores some of the inter-relationships in the WHO model of functioning and disability. Specifically, it investigates participation in work, and examines relationships among participation and performance of work activities, personal factors, environmental factors, and the impact of a health condition: rheumatoid arthritis.

Rheumatoid arthritis (RA) is a chronic illness that is typically diagnosed at early to mid-adulthood (Goronzy & Weyand, 1997), the peak productive years for most adults in

terms of both paid and unpaid work responsibilities. RA is a systemic connective tissue disease that predominantly affects the synovial joints in the hands, wrists, elbows, shoulders, neck, hips, knees, ankles and feet (Anderson, 1997). Joints become swollen and painful, and prolonged periods of inflammation result in damage to joint cartilage, bone, and surrounding tissues (Anderson, 1997). Systemic features include fatigue and general malaise. RA is characterized by exacerbations and remissions, and is generally viewed as a progressive condition. The effects of the disease on individuals vary, and range from mild pain and limitation in joint mobility to severe impairment causing major limitations in activities of daily living (Anderson, 1997). There is no cure, but there are several lines of drug therapy that may effectively control symptoms and retard the deleterious effects on the joints (Paget, 1997). Additionally, occupational therapy, physical therapy, counseling, orthopedic surgery and other interventions assist people with RA to manage their symptoms, adapt to the demands of living with a chronic illness, and maintain their ability to participate in their chosen activities (Paget, 1997).

The distribution of RA is worldwide, involves all ethnic groups, and affects women about 2.5 times more than men (Goronzy & Weyand, 1997). With a prevalence of approximately 1% (Goronzy & Weyand, 1997), almost 300,000 Canadians have RA, which is one of over 100 types of arthritis. In an attempt to estimate the prevalence of disabling arthritis in Canada, Badley (1995) examined data from the 1987 Canadian Health and Activity Limitations Survey (HALS) and 1990 Ontario Health Survey (OHS). The HALS was a national survey of 132,337 people living in households and 18,100 people living in health care institutions, all over the age of 16 years, as identified by a screening question on the 1986 Canada census. The OHS was a stratified cluster sample of people living in households in Ontario, and data from 45,650 people over the age of 16 were available for Badley's analysis. Of all HALS respondents reporting arthritis, only slightly more than 11% were employed, compared to almost 64% of non-disabled adults. The overall prevalence of disabling arthritis, defined as self-reported activity restrictions, was 2.7%, and this was the leading cause of long-term disability among HALS respondents (Badley, 1995). Among OHS respondents, 2.3% reported arthritis as a cause of disability, which was defined as limitations in normal activities (Badley, 1995). These analyses suggest that 700,000 or more

Canadians are not able to pursue normal daily activities due to some form of arthritis. How many of these respondents had RA is not known, because precise medical diagnoses could not be verified in the population surveys. Nevertheless, the data indicate that a substantial number of adults are adversely affected by arthritis in terms of maintaining employment or engaging in daily activities such as household work.

1.2 Purpose of the Study

The purpose of this study was to investigate factors associated with participation in paid and unpaid work by adults with rheumatoid arthritis (RA).

While there is no cure for RA, some of the factors associated with limitations in the performance of paid and unpaid work may be amenable to rehabilitation interventions. If these factors are identified, rehabilitation and education strategies can be developed to assist people with RA maintain or resume their participation in paid and unpaid work.

As treatments have improved over the years, so has the quality of life of people with RA. Advances in medications have shown that disease progression can be slowed; advances in exercise physiology have shown that physical capacity can be maintained and improved without harm to vulnerable joints; and advances in patient education strategies, most notably the Arthritis Self-Management Program, have shown that enhancing self-efficacy can reduce arthritis symptoms and decrease the number of visits to physicians (Lorig & Holman, 1993; Lorig, Mazonson, & Holman, 1993). The ultimate aim of this research is to inform providers of rehabilitation and education programs of suggested content for inclusion in programs aimed at maintaining or improving participation in paid and unpaid work by adults with arthritis.

1.3 Definition of Terms

An *occupation* is any meaningful activity in which people engage (Canadian Association of Occupational Therapists, CAOT, 1997). People have many occupations and occupational roles, because occupations encompass all goal-directed self-care, productive, and leisure activities that individuals need or want to do in the context of their daily lives. Used this way, occupation reverts to its roots, and is used to describe anything people do to occupy their time. It is not limited to activities with monetary or economic value. This is a broader definition than assumed in everyday conversation, which typically defines occupation as synonymous with a paid job, although it is accepted that some people may identify their occupation as homemaker, student, or retired. The focus of the present study is limited to productive occupations, and it does not explore self-care occupations (like eating and dressing) or leisure occupations (those pursued for relaxation and recreation). Productive occupations have been categorized as *paid work* and *unpaid work*.

Paid work refers to employment of any kind, including full-time, part-time, contract work and self-employment. *Participation* in paid work refers to the time spent in all types of employment. This is compatible with the definition of paid work used by Statistics Canada: "all functions directed toward market activity" (Statistics Canada, 1999). In much of the literature reviewed to inform this study, the term *work disability* refers to changes in people's ability to engage in paid work. Most commonly, *work disability* is defined as cessation of employment.

Unpaid work refers to productive activities people do to maintain their home, family, and community, for which they are not paid a salary. Examples are housework (cooking, cleaning), home maintenance (repairs, yard work), childcare, care given to ill family members, and volunteer work. It also includes going to school, which is generally an unpaid but productive role, when pursued to gain qualifications to enter or advance a career. Courses taken for fun and relaxation would, however, be classified as leisure occupations and not unpaid work. Note that for some people, some forms of unpaid work are employment (as in the case of a housekeeper hired to clean a home), in which case it would be classified as paid work for that person. *Participation* in unpaid work refers to the time spent doing

unsalaried productive activities at home or in the community, or "all work directed toward non-market oriented activity" (Statistics Canada, 1999).

Together, *paid and unpaid work*, or *total work* refers to all of the productive occupations in which a person engages (Lombardi & Ulbrich, 1997). In the present study, *participation in paid and unpaid work* is operationally defined as the self-reported number of hours of unpaid work plus the number of hours of paid work in a given week (Frederick, 1995; Lombardi & Ulbrich, 1997).

1.4 Arthritis and Paid Work

Participation in paid work is an issue for people with rheumatoid arthritis because a large proportion of them will stop work prematurely due to their disease. In a review of four clinical and two population studies conducted in the United States, Yelin (Yelin, 1995) cited work disability rates for adults with RA or osteoarthritis (OA) ranging from 51% to 72%. In all six studies, work disability was defined as cessation of employment. RA was a confirmed diagnosis in the clinical samples, while RA and OA were presumed diagnoses in the population surveys, based on the reported symptoms being consistent with diagnostic criteria. Work disability rates tended to be higher among those meeting stringent diagnostic criteria than in population surveys. Yelin also analyzed data from the Health and Retirement Survey (a national probability sample of Americans aged 51-61 years of age) to estimate trends in work loss in various subgroups of respondents. His estimates are in Table 1. The results from this survey suggested that as arthritis symptoms persisted and required medical attention, the proportion of adults who discontinued paid work increased.

38%
41%
53%
60%

Table 1. Self-reported Rates of Work Loss Among Americans Aged 51-61 Years.

MacKinnon and colleagues (MacKinnon, 1992; MacKinnon, Avison, & McCain, 1994) investigated occupational profiles and psychological adjustment among adults with RA in London, Ontario. Using a case-control design with adults aged 18-65, they investigated time use (the 'occupational profile') and self-reported depression, anxiety, and life satisfaction ('psychological adjustment'), and the association between occupational profiles and psychological adjustment. The RA participants (n = 128) were volunteers from the caseloads of rheumatologists at University Hospital in London, Ontario. Municipal assessment files were used to identify appropriate comparison subjects (n = 124) living in the same neighbourhoods as the RA subjects, in the case of urban settings. For rural areas, control subjects were identified with the assistance of the epidemiologist in the local health unit. All participants were interviewed in their homes for information on age, sex, marital status, employment status and household income, and completed self-report measures of depression, anxiety, mastery, social support, and functional status. Participants completed a 7-day diary listing the hours devoted to all of their daily activities.

Occupations were classified into 12 categories: market (paid) work, house/yard work, child care, services/shopping, education, personal care, participation in organizations, social entertainment, active leisure, passive leisure, rest, and sleep. On average, the RA group spent 15 hours per week in paid work, which was significantly less than the weekly average of 24 hours for the control group (p < .05). However, a larger proportion of the controls were employed (68%) compared to the RA subjects (43%), and MacKinnon did not compare the hours of employed RA subjects to employed controls, or report if the RA subjects were working less (or not at all) due to their arthritis or for another reason. Among the individuals with RA, hours of work were significantly and inversely correlated with functional limitations, number of joints involved, and pain. A multivariable analysis was not reported, so the relative importance of these factors was not identified. Individuals with RA who worked less than 35 hours per week reported significantly more depression, less mastery, and lower self-esteem than the RA subjects who worked more than 35 hours per week. This was the only case-control study on work and RA found in the literature and, although it had limitations, it suggested that people with RA engaged in less paid worked than those without RA.

Several investigators have sought to identify risk factors for work disability among people with arthritis. Some studies are specific to RA, while others are based on broader samples including more than one type of arthritis or the more global category of musculoskeletal conditions. Those studies pertinent to people with RA are described below.

Yelin, Henke and Epstein (1987) described the employment history of persons with RA, the incidence and prevalence of work loss over time, and risk factors for work loss. A panel of individuals with RA was formed in 1982-83 by randomly sampling one-half of the rheumatologists in northern California (n = 57). Seven were no longer in practice and 10 declined to participate. The 40 participating rheumatologists listed all patients who met strict criteria for RA and presented prospectively during a one-month period (n = 847). Of these, 822 (97%) were interviewed. The initial interview included questions about symptoms, functional status using the Health Assessment Questionnaire, (HAQ; Fries, Spitz, & Young, 1982), employment status, use of health care providers and health insurance. In 1984, 754 (92%) of the original cohort were re-interviewed. In 1985, 698 were re-interviewed (93% of 754, 85% of the original 822). At baseline, 390 reported working for pay at some point in their lives, and were young enough to still be under 65 years of age in 1985, the time of the follow-up interview. Ninety-one percent of this group of workers (n = 353) was interviewed in 1985.

Incidence and prevalence of work disability were calculated using life table methods and questions about work cessation and year of diagnosis. Ten percent of the sample stopped work within one year of diagnosis, and the incidence of work disability ranged from 2.5% to 10% for each of the next 13 years after diagnosis. The prevalence of work disability five years after diagnosis was one-third of the sample, and after 10 years it was almost one-half. Logistic regression was used to estimate risk factors for stopping paid work, with employment status as a dichotomous variable (employed or not employed). At the time of the follow-up interview in 1985, 143 had stopped working, 106 had the same job, and 57 had changed jobs. Of those who had stopped working 119 (83%) had done so due to their RA. Declining functional level (i.e., increase in HAQ score), age and characteristics of work (e.g., type of industry, physical activities required at work) were shown to have the greatest impact on probability of work loss. The relative risk for work loss associated with the HAQ score was greater than 3. Among the demographic variables studied, only age reached statistical significance as an explanatory variable, with a relative risk of 1.73. Job loss was most strongly influenced by the characteristics of the job itself: as discretion over job activities (job autonomy) decreased and physical demand increased, the probability of stopping work

increased. A one standard deviation increase in the number of physical activities required on the job multiplied the risk of work disability by 1.5; a one standard deviation increase in the worker's discretion on the job reduced the probability of work disability (RR = 0.28). Service industry workers were about twice as likely as other workers to stop working. Indicators of disease severity were not significantly associated with job loss, nor were demographic characteristics of gender or educational level.

These findings are consistent with previous findings from the same authors who analyzed data from a US social security administration population survey (Yelin, Henke, & Epstein, 1986). This survey was designed to provide estimates of the prevalence of work loss associated with illness and injury. The authors reviewed data from a subset of respondents, those who had worked for pay at some point prior to the onset of illness and who currently had a chronic condition resulting in activity limitation, n = 3529. Of this group, 429 omitted questions on critical variables, leaving a final sample of 3100. Work outcome was a dichotomous variable defined as "not working and not looking for work" versus "working, on temporary leave and/or looking for work." Logistic regression models were constructed to evaluate work outcome in relation to many variables, including medical conditions (e.g. musculoskeletal symptoms), functional status (limitations with activities of daily living), physical requirements of the work, knowledge of and eligibility for disability benefits, and attitudes toward work (e.g., did they like working). Of those reporting musculoskeletal symptoms, 72% were not working. However, musculoskeletal symptoms such as the number of painful joints were not significantly related to work outcome. Of all variables included in the models, the nature of the work itself had the most profound impact on work outcome among musculoskeletal disease patients. People in professional occupations had a lower probability of job loss than those in other occupational categories, and people in service occupations had higher rates of job loss. Good working conditions (an interaction variable created from the demands of the job and the limitations one experienced in performing them) lowered the probability of work disability by 57%.

Yelin and colleagues (Yelin, Meenan, Nevitt, & Epstein, 1980) also explored the relative contribution of selected variables on work disability status in adults with RA who

had been working at the time of disease onset. Their sample came from 25 different rheumatologists practicing in various settings in Boston and San Francisco, who logged all patients presenting with RA in a one-month period. Patients with another chronic illness that could affect work status were excluded, as were any who were older or younger than the age span of 21-65 years. The final sample (n = 245, 89% of those eligible) was interviewed by telephone. The average time since the onset of RA at the date of the interview was 10 years. Sixty percent of the sample had stopped working at the time of the interview. The analysis of risk factors was limited to the 180 respondents who were employed in the pre-morbid year (78 males and 102 females). The outcome was binary, employed versus disabled (total cessation of work). Data were analyzed using contingency tables and discriminant analysis, a technique that calculates the percent of cases correctly classified as employed or disabled by the independent variable in question. The results were presented in terms of the probability of work disability. As disease duration increased and stage of disease worsened, the probability of work disability increased. Single people had a lower probability of work loss (0.33) than did those who were or had been married (0.61, 0.67 respectively). Premorbid income below the sample mean also significantly predicted work loss (probability = 0.66), but no other demographic characteristics were significant (age, gender, race, educational level). Among the work factors studied, only those related to autonomy significantly affected the probability of job loss: 0.62 for those not self-employed; 0.66 for those who had little control over work pace, and 0.66 for those with little control over work activities. Occupational classification and physical demands did not affect the probability of work loss. In the multivariable discriminant analysis, 80% of the respondents were correctly classified using a model that included disease factors (disease duration, medications, prior surgery), social factors (marital status, premorbid income), and work factors (control over work pace and activities, self-employment status, and occupational group).

Callahan, Bloch and Pincus (1992) investigated work disability and RA using an existing data base of RA patients from three Nashville clinics. The data base contained information on 259 patients with RA seen during 1984-1986, of whom 175 had been working full-time at disease onset. Of this group, 36 patients continued to work full-time and 55 were receiving work disability payments (which was the authors' definition of work-disabled) at

the time of their assessment. These 91 patients comprised the sample for analysis. The average age of the sample was 52 years, and 41% were female. It is perhaps worth noting that this was the only study reviewed in which the sample was predominantly male. Data were analyzed using multiple logistic regression and recursive partitioning. Recursive partitioning is a non-parametric technique that results in a classification tree with branches that bifurcate on the factor that produced the two most distinct sub-groups.

Older age, less education, and non-professional/non-managerial job title were all significantly associated with work disability, as were several clinical factors (such as longer disease duration, more active joints, greater joint pain and less joint mobility). Functional measures were also predictive of work disability, including lower grip strength, slower walking time, slower hand dexterity (using a standard button board), and greater difficulty, dissatisfaction, and pain associated with activities of daily living. Gender, race, and marital status were not significant, as was the case with morning stiffness and all laboratory measures (erythrocyte sedimentation rate, rheumatoid factor, and HLA-DR4), and a global self-assessment of overall health.

In the recursive partitioning analysis, the first variable splitting the sample was difficulty with activities of daily living. Subsequent factors were disease duration, age, and occupation (non-professional/managerial vs professional/managerial). The authors concluded that in "the multivariate analyses, using both regressions and a classification tree, if the patients' occupation, age, duration of disease and functional status measures were known, other physical examination, radiographic and laboratory measures added relatively little to the identification of whether an individual was working full-time or receiving disability payments" (p. 15). This has implications for the assessment of work disability and recommendations for benefits, which have traditionally relied on physical examination rather than functional status measures.

More recently, Allaire, Anderson and Meenan (1996) conducted a cross-sectional mail survey of adults with RA from across the United States. They recruited their sample by contacting colleagues in the four US census regions to request names and addresses of five patients with RA from each practitioner. Of 987 potential subjects contacted, 703 (71%)

responded, of which 132 were ineligible and 72 declined to participate. Surveys were sent to 496 individuals (3 could not be contacted), and 469 were returned (95% of surveys sent; 82% of eligible respondents). The mean age of the sample was 47 years (20-64 years), 76% were women, and 72% were married.

The dependent variable was work status (employed versus not employed). The potential explanatory variables studied were demographic (age, education, race, marital status, number of dependents); disease status at the time of questionnaire administration (joint pain, functional status, duration of RA, co-morbidities); work characteristics (physical demand, autonomy, job type/industry, employer size); social support or help available (co-worker support, employer help, household responsibilities and help), and difficulty commuting to work. Data were analyzed using logistic regression. Attributable fractions were calculated using multiple logistic regression. Risk factors were dichotomized at the mean score for work-disabled subjects, and subjects were considered 'exposed' if their score was higher than the mean. The adjusted attributable fraction was the proportion of work-disabled subjects exposed multiplied by (aOR-1)/aOR, where aOR was the odds ratio for that risk factor adjusted for all other factors in the model. Recursive partitioning, a non-parametric analysis, was also carried out.

In Allaire and colleagues' sample, 22% of the participants were work-disabled (no longer employed). Factors significantly related to work disability and their attributable fractions were more severe disease (a variable combining functional status and joint pain, 57%), non-managerial or non-professional job title (42%), greater physical demand on the job (30%), difficulty commuting to work (30%), longer disease duration (24%), lower pre-morbid income (22%), older age (19%), and lower co-worker support (15%).

In the recursive partitioning analysis, the first bifurcation was disease severity, which split the group into 59 people with more severe disease of whom 75% were work-disabled, and 410 people with less severe disease of whom only 14% were work-disabled. Subsequent factors were disease duration, age, job physical demand, co-worker support, commuting difficulty and pre-morbid income. The authors concluded that both individual disease status variables and work-related variables were major predictors of work disability. Unlike other

studies, job autonomy did not emerge as a significant factor. Of the significant predictors of work disability, job physical demand and commuting difficulty were identified by the authors as being potentially amenable to intervention strategies. Other variables may also be amenable to intervention. For example, disease status may be modifiable to a degree through self-management programs and assistance to develop adaptive or compensatory strategies (since disease status was defined as pain and functional status); and job type could be altered with training programs that enable people to change jobs.

In an attempt to recognize that paid work is influenced by responsibilities in the home, Reisine and colleagues (Reisine, Grady, Goodenow, & Fifield, 1989) studied a convenience sample of 122 women with RA who had been employed in the year prior to diagnosis. They tested the explanatory variables used by Yelin and colleagues in an earlier study (Yelin et al., 1980) and added family responsibilities to the list of variables, which were measured as instrumental functions (time spent cooking, cleaning and shopping) and nurturant functions (making arrangements for family members, caring for ill family members). Work disability was defined as no longer working in paid employment. A stepwise multiple logistic regression indicated that lower functional status (as measured by the HAQ), followed by lower job autonomy and more physically demanding work were the strongest predictors of work disability. Increasing age, fewer instrumental responsibilities at home and less social support were also significantly associated with work disability.

In another study, this time using a national sample of patients with RA, Reisine, McQuillan and Fifield (1995) examined predictors of work disability in 392 adults followed over five-year period. A panel of patients with RA was established by selecting a random sample of 116 rheumatologist-members of the American College of Rheumatology, of which 56 agreed to participate by distributing response cards to eligible patients with RA. One thousand and forty-nine patients returned cards releasing their name and address, 921 returned consent forms for a telephone interview and release of medical records and, in the fifth year, 699 were available for follow-up interviews. The work disability analysis was limited to 392 respondents who had been employed at time of study enrolment and remained in the study for the full 5 years. At year five, the mean age was 48 years and 72% were

female. The dependent variable was work status in year five, a dichotomous variable: employed outside the home versus not employed. The potential explanatory variables were derived from a 100-item baseline (year zero) interview including demographic information, health status, work-related factors, family responsibilities, and social support. Multiple logistic regression was used to determine which baseline variables had a significant effect on predicting work cessation five years later. A hierarchical approach was used, testing variables that had been significant in previous studies and entering variables in 6 conceptual blocks (demographic, self-reported disease status, physician-reported disease status, work characteristics, work attitudes, and family responsibility/social support).

At year five, 257 (66%) were still working. Variables significantly associated with work disability were older age, more deformed joints, more inflamed joints, less complexity in working with things on the job (determined using job titles from the Dictionary of Occupational Titles), and the desire to remain employed. The two disease-related factors that were significant were both physician-reported variables (joint deformities and inflamed joints), none of the self-reported health status variables were significant. Interestingly, factors associated with work disability in previous studies, including home responsibilities, presence of children, HAQ disability scores, perceived pain, control over paid work activities (job autonomy), and income did not emerge as significant factors in this prospective analysis. The reason for these differences is unknown, but the authors offered several possible explanations, including the possibility of recall bias in the measurement of work characteristics in prior studies. Their study measured work characteristics while respondents were still employed and used these measures to predict the outcome 5 years later, whereas prior studies asked respondents to think back to when they were employed. Reisine and colleagues (1995) also noted that when additional variables are studied, they may mediate the effect of previously significant variables.

Wolfe and Hawley (1998) interviewed 823 patients with RA referred to the Wichita Arthritis Center regarding their employment history. Beginning in 1974, they enrolled consecutive patients in a data base in which a variety of demographic, clinical and self-report variables were collected at each patient visit. The purpose of the interviews (conducted in

1994) was to determine the rate of work disability, the risk factors associated with work disability, and the relative predictive ability of the variables collected at the first visit, compared to serial data. The 823 patients interviewed were volunteers from among 1563 patients in the data bank. Two-hundred and ninety-six had died, 36 were in nursing homes, 189 declined to participate in the detailed interview, 70 were lost to follow-up, and contact had not been made with 149 patients at the time of study closure. Work disability was defined as quitting work because of arthritis or retiring early because of arthritis. Among the total sample, 100% of the men and 87% of the women had been employed outside the home at some time in their life. Analysis of work disability, though, was limited to the 509 patients who were employed at the time they were diagnosed with RA. The sample was 37% male, and had a mean age of 50 years at study entry.

Kaplan-Meier survival curves were used to estimate the risk of work disability. Work disability was reported by 37.7% of the sample. The 25% survival time was 6.4 years, and based on the survival function, 22% and 32% would have stopped working after 5 and 10 years, respectively, following onset of RA. This was a better 'survival time' than previous studies, which reported closer to 50% of people with RA had stopped working within 10 years of diagnosis (Callahan et al., 1992; Doeglas et al., 1995; Mau et al., 1996; Reisine et al., 1995; Yelin et al., 1987). Wolfe and Hawley (1998) suggested a selection bias as one possible explanation for differing results, with a tendency toward more severe RA cases in some studies compared to their sample of sequential referrals. Additionally, they noted that their sample had a large proportion of rural farmers, which may be different from the composition of other samples.

Wolfe and Hawley (1998) also attempted to identify predictors of work disability. In multivariate Cox regressions using results of the first clinic visit as potential predictors (n = 456), the following were significantly associated with work disability: more pain, moderate to heavy work (compared to light or sedentary), being female, having a positive rheumatoid factor, lower educational level, and higher body mass index. This analysis was repeated using the mean score from all clinic visits for the potential predictors that change over time (e.g., pain scores). The significant factors in the second analysis were higher erythrocyte

sedimentation rate, lower functional status (higher HAQ score), moderate to heavy work type, more pain, lower educational level, and gender (being female). The authors then plotted survival curves for each of these risk factors, to assess their independent contribution to work disability. In general, the curves suggested that the effect of education, pain, and elevated ESR occur quickly, while the effect of obesity is delayed, occurring much later in the course of the disease. For example, half of those with less than high school education had stopped work after 5 years, compared to one-quarter of those with a post-secondary education.

Only one of the preceding studies identified gender as a significant predictive factor (Wolfe & Hawley, 1998), however most of the samples were predominantly female, one exclusively so. De Roos and Callahan (1999) designed a cross-sectional study specifically to examine differences by sex in the correlates of work status among adults with RA. They hypothesized that the relative importance of factors explaining work disability was likely to differ between men and women because of the societal context that influences role expectations and work performance. The study sample was derived from a data base of 1416 patients with RA recruited from the practices of 15 rheumatologists in six states (CA, FL, ID, MN, PA, TN) and Washington, DC. The work status study was limited to the 960 patients considered to be working age (18-64 years at time of baseline assessment). Data were collected with a mail survey. Work status was defined using responses to the question "At this time, are you (please check all that apply): working full-time; working part-time; homemaker full-time; homemaker, need help from others; doing volunteer work; retired; student; disabled, receiving disability; disabled, receiving no disability; temporarily laid off; unemployed seeking work; on leave without pay; other (describe)." Those who checked working full or part-time or who worked in addition to being a homemaker were classified as "working." Those who reported being disabled, regardless of the receipt of disability payments, were classified as "work disabled." They also created a second, broader classification of non-participation, a "not working" category that encompassed the work disabled and all other non-participants in the paid work force.

Demographic data included sex, age, race, marital status, education level, date of onset of RA, and current or past occupation (using a list of 12 categories). The modified HAQ was used to assess difficulty and pain associated with performance of activities of daily living. The helplessness subscale of the Rheumatology Attitudes Index was used to measure helplessness. The continuous variables of education level, disease duration, functional difficulties, pain and helplessness scores had non-linear relationships to work status, and were therefore converted into categorical variables prior to analysis using logistic regression. Two sets of analyses were done, comparing working with work-disabled subjects, and comparing working and not working subjects. Within each set, the association of explanatory variables with work status was examined for the total cohort and separately for each gender group.

Women comprised 77% (740) of the study sample. Four hundred and fifty-one respondents were working, 508 were not working (of whom 254 were work-disabled) and work status was missing for one subject. Comparing working with work-disabled subjects, women were more likely to be work disabled than men (OR = 1.7, 95% CI 1.02-2.89). The odds of being work-disabled increased with older age, longer disease duration, and higher HAQ disability scores in the total sample as well as each gender group. Among the women, the odds of being work-disabled increased if they had less than a high school education, worked in a non-professional/non-managerial occupation, and reported more pain. These variables were not significant correlates for men. Men who were not married were more likely to be work-disabled than married men, but marital status was not significant for women. Men with high helplessness scores were also more likely to be work-disabled, but this variable was not significant for women. The analysis comparing working and not working groups indicated that the odds of not working was more than 3 times greater for women than men (OR = 3.47, 95% CI 2.32-5.19), which was expected with the inclusion of homemaker in the not working category. Otherwise, this analysis provided similar results to that comparing working and work-disabled subjects, though the associations were not as strong. Overall, this study substantiated several correlates of work disability found in previous studies: older age, longer disease duration, lower functional status, lower educational level, more pain, and non-professional/non-managerial jobs had all been

previously identified as risk factors for work cessation in people with RA. However, the sex differences had not been explored in past studies, and the different findings for men and women on some variables may warrant further study. For example, if these results are verified in future studies, they suggest different rehabilitation strategies for men and women in order to reduce the risk of job loss: re-training may be more important for women than men, and strategies to mediate feelings of helplessness may be more important for men than women.

So far, the studies cited have investigated risk factors for work disability among samples of American adults with RA. What about work disability in other countries? A handful of international investigations was found. A study in the Netherlands focused on adults in the early stages of RA, with subjects who had been diagnosed less than 5 years previously (Doeglas et al., 1995). The investigators screened 366 consecutively referred patients to their out-patient clinic, and 292 patients met the criterion of early disease. Of these, 119 had been employed at the time of diagnosis, and this group comprised the study sample (mean age = 48 years, mean disease duration = 1.8 years, 36% male). Participants were interviewed in their homes, regarding their functional status (using the HAQ, and Groningen Activity Restriction Scale, GARS), educational level, job title and paid work activities. Employment status was a categorical variable for initial descriptive purposes (employed, working less due to RA, on sick leave due to RA, quit job due to RA), but was dichotomized as work disability (employed versus not employed) for subsequent analyses.

Logistic regression with work disability as the dependent variable indicated that of the demographic variables, only educational level contributed significantly to the prediction of work disability (OR = 3.1), associating lower education with higher risk. Age, gender and job type did not enter the model. Of the variables related to disease status, longer disease duration, lower functional status (higher HAQ score) and higher erythrocyte sedimentation rate (ESR, a laboratory measure of disease activity) were significantly associated with work disability. The GARS score, active joint count, and type of medical treatment did not. The model containing education, functional status (HAQ), disease duration and ESR correctly classified 81% of the subjects. This was one of the first studies of patients with early disease

(less than 5 years duration); the following study selected patients with even shorter disease duration.

In preparation for a large-scale prospective study, Mau and colleagues investigated the occurrence of work disability in a pilot study of 132 adults with early RA (\leq 12 months) followed for an average of 6 years (Mau et al., 1996). Participants were working age adults (18-60 years) presenting with early RA to an out-patient clinic in Germany between December 1982 and September 1987. Demographic, disease-related, and work-related characteristics were measured at time one (study entry) and time two (a mean of 6 years later, SD = 2 years). At time two, 2 patients had died, 2 had moved, and 19 refused further participation. There was no difference in baseline characteristics between the 109 who remained at time two and those who were lost to follow-up. Of the 109 available at time two, 73 had been employed at baseline. Participants who had stopped working were asked for the date of work loss and the reason for it. The definition of work-disabled was total cessation of employment due to RA and receipt of a social security pension, a decision based on criteria in the German Social Security Law. Continuous variables were categorized to permit analysis with recursive particioning and Cox regression.

By time two, 27 of the 73 patients were work-disabled, 6 had retired on reaching normal retirement age, 6 stopped working due to RA but did not receive a social security pension, and 34 were still employed. The first factor in the recursive partitioning analysis was age: people over 50 were significantly more likely to be work disabled. Subsequent significant factors were higher erythrocyte sedimentation rate (ESR, an indicator of inflammation), work that required precision or writing, longer disease duration, more active joints, and lower functional status [measured by the physician using the American College of Rheumatology's functional classes (Klippel, Weyand, & Wortmann, 1997), expanded to a 7point scale.] In the multivariable Cox regression analysis using a forward stepwise procedure, the significant predictors in order of entry were older age, lower functional status, longer disease duration, precision work/writing required at work, more active joints, positive rheumatoid factor, and presence of erosive changes on x-ray. The first five factors in the Cox regression were the same as the factors arising from the recursive partitioning procedure. The ESR, significant in the recursive partitioning technique, did not enter the multivariable Cox model. Gender, morning stiffness, type of work, and the physical requirements on the job of grip force, overhead work, and lower extremity strain were not significant. The relatively small sample for the number of variables studied may threaten the stability of the results.

Fex and colleagues (Fex, Larsson, Nived, & Eberhardt, 1998) in Sweden reported a prospective study of the course of RA in 106 patients followed over 8 years. Consecutively referred out-patient clinic patients who had joint symptoms for less than 2 years entered the study. One aspect of the study was the development of work disability, which was followed in the 86 patients who were employed prior to disease onset. By study end, 44 were still employed, 27 full-time and 17 part-time, 23 were work-disabled, and 19 had retired. Factors measured at baseline and considered in logistic regression analyses were age, gender, marital status, education level, HAQ disability score, number of active joints, number of damaged joints, pain, psychological distress, job type, job physical demand, job autonomy, and satisfaction with work. Models constructed using work status at study end as the outcome did not predict work disability any better than chance, and the authors presumed this result to be due to only 67 patients still of working age at study end. Logistic regression was then conducted using work status at the mid-point of the study (year 4) as the dependent variable, with the 81 patients of working age that year. With this group, lower functional status (higher HAQ score), older age, and having less than a high school education were significant predictors of work disability (employment cessation). None of the other factors studied were significantly associated with work disability. The authors also noted that 32 (78%) of the employed patients had made substantive changes to maintain employment: 15 changed jobs, 13 changed work tasks within the same job, 8 modified their workplace, 15 reduced their hours of work, and 4 had re-education (numbers do not sum to 32 because some patients undertook more than one change). But because the work disability outcome was cessation of employment, factors associated with these changes in work status were not captured in the predictive analysis. These may be important aspects for future studies to identify factors associated with work retention.

A Finnish prospective study followed 82 patients with RA for an average of 10 years to evaluate the development of work disability (Sokka, Kautianinen, Mottonen, & Hannonen, 1999). Respondents were recruited from two other RA study groups, n = 135, and were eligible for the work disability study if they had been employed at the onset of their RA. On average, they were 40 years of age at study entry, with disease duration of 6.4 years, and the group was 73% female. The outcome was permanent work loss prior to usual retirement age of 65 years, due to RA, and this self-reported date was verified using disability certificates. Other variables measured were educational level (>12 years, 9-12 years, <9 years), occupation type (blue collar, white collar, self-employed), physical demands of the job (sedentary, moderate demand in sales and services, and physically demanding manufacturing and agricultural work), joint erosions, active joints, rheumatoid factor, disease duration, and pain and general well-being on 100 mm visual analog scales. Functional status was measured with the HAQ, but only for half of the sample so it could not be included in analyses.

A Kaplan-Meier survival curve illustrating the cumulative probability of work retention showed the steepest decline in work rates in the first two years after diagnosis. By year two, the probability of remaining employed was 77% (95% CI = 86 to 69%). By year 8, it had declined to 62% (CI = 51 to 72%). At study end, 46 patients continued to work and 36 were work disabled. Risk factors for work disability were identified using Cox regression and a subset of eight potential explanatory variables. Significant factors associated with work cessation were older age, more active joints, and more physically demanding work. Gender, marital status, rheumatoid factor, occupational class, and educational level were not significant risk factors.

Only one recent Canadian study of work disability and RA was found, in conference proceedings, so complete study details are not yet published. Lacaille and colleagues (Lacaille, Sheps, Spinelli, & Esdaile, 1999) conducted a cross-sectional survey of adults aged 18-65 years of age who had used the services of the Arthritis Society, British Columbia & Yukon Division, in the period 1991-1998. Of the 1824 potential subjects identified, 951 responded to an invitation to participate. One hundred and thirty were not eligible and 240

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refused to participate, leaving a final sample of 581. Subjects were classified as working if currently employed, and work disabled if they had not worked for at least 6 months because of their RA. Potential risk factors for work disability were measured at the time of survey administration in the working subjects, and were recalled to the time of job loss in the non-working subjects.

Thirty-five percent (n = 203) were work disabled. Survival analysis showed that work disability started early and continued at a steady rate (7.5% at one year, 18% at five years, 27% at 10 years after diagnosis). This is a lower rate of job loss than suggested in some of the above-cited studies, but similar to that reported by Wolfe and Hawley (1998), who also recruited participants from an arthritis center data base (in Wichita, KN). In Lacaille et al.'s univariate analyses, several work-related factors were significantly related to work loss, including job autonomy, physical demand, commuting difficulty, co-worker and employer support, and use of vocational services. In multiple step-wise logistic regression analysis, functional status (as measured by the HAQ) and perceived pain were the only sociodemographic or disease-related variables selected in the final model. There were seven significant work-related variables. Those who were work-disabled were more likely to report difficulty commuting to work, and had received some type of employer help that was likely to reduce their productivity in the workplace. Those who were self-employed, perceived their work to be important, had received ergonomic modifications to their work station, received greater support from family members and felt comfortable telling co-workers about their RA were less likely to be work-disabled.

The preceding studies each attempted to identify risk factors for work disability. Table 2 (page 24) summarizes many of the factors studied and those that were significantly associated with work disability in the multivariable analyses in 12 studies. These include factors associated with the work itself, aspects of the social and physical environment, and characteristics of the individual. Although some studies identified similar predictors of work disability, there were also inconsistencies across studies. For example, increasing age was associated with work disability in most of the studies in which it was included as a potential predictor in multivariable analyses, as was lower functional status. (The inconsistency

indicated in Table 2 in the Doeglas et al. (1995) study refers to more than one functional measure being used. Lower functional status measured by the HAQ was associated with work disability while two other functional measures were not). Age, disease duration, pain, non-managerial/non-professional job type, physical demand of the job and job autonomy were significant predictors in some but not all studies in which they were investigated. Women were more likely to be work disabled in two out of 11 studies. Job satisfaction was not a significant predictor in the three studies in which it was assessed. Co-worker support was significantly associated with work retention in the one study that evaluated it as a distinct form of social support (Allaire et al., 1996). Less social support was associated with work loss in one cross-sectional study, but was not significant in a longitudinal study conducted by the same authors (Reisine et al., 1989; Reisine et al., 1995).

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	First Aut	hor and Yea	ur of Publics	ation:								
сал ^а	Allaire 1996	Callahan 1992	De Roos 1999	Doeglas 1995	Fex 1998	Mau 1996	Reisine 1989	Reisine 1995	Sokka 1999	Wolfe 1998	Yelin 1980	Yelin 1987
Study Design	x-sec	X-Sec	X-Sec	X-Sec	long	long	x-sec	long	long	long	x-sec	long
Sample Size	469	91	096	119	81	73	122	392	82	456	180	353
Factors:												
Age (older)	+	÷	+	ı	÷	+	+	+	+	t	•	+
Education (less)	•	+	-/+	+	÷	DNS	ı	I	•	+	•	·
Gender (female)	•	I	÷	•	I	I	DNS	I	•	÷	•	•
Race (non-white)	•	1	÷	DNS	DNS	DNS	DNS	DNS	SNG		•	DNS
Premorbid income (lower)	+	DNS	DNS	DNS	DNS	DNS	DNS	ı	DNS	DNS	+	DNS
Married		ı	-/+	DNS	1	DNS	•	T	1	I	+	1
Children	1	DNS	DNS	DNS	DNS	DNS	DNS	I	DNS	DNS	DNS	DNS
Active joints (more)	+	+	DNS	•	ı	+	DNS	+	+		I	+
Disease duration (longer)	+	+	+	+	DNS	+	•		DNS	ı	+	1
Sedimentation Rate (higher)	DNS	P	DNS	+	DNS	+	DNS	DNS	DNS	+	DNS	DNS
Rheumatoid factor (positive)	DNS	I	SNQ	DNS	DNS	+	DNS	DNS	ı	+	SNG	DNS

 Table 2. Factors Associated with Work Disability from Multivariable Analyses Reported in the Literature.

 Legend:
 cross-sectional (x-sec); longitudinal (long); significant association (+); no association (-); conflicting results (+/-); did not study (DNS).

.../continued

Table 2. Factors Associated with Work Disability from Multivariable Analyses Reported in the Literature, continued.Legend:cross-sectional (x-sec); longitudinal (long); significant association (+); no association (-); conflicting results (+/-); did not study (DNS).Legend:cross-sectional (x-sec); longitudinal (long); significant association (+); no association (-); conflicting results (+/-); did not study (DNS).Summary limited to factors included in at least two studies.

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	First Auth Allaire 1996	or and Year Callahan 1992	of Publica De Roos 1999	tion: Localas 1995	Fex 1998	Mau 1996	Reisine	Reisine 1995	Sokka 1999	Wolfe 2 1998	Yelin 1980	Yelin 1987
Joint deformities (more)	DNS	+	DNS	DNS	DNS	DNS	DNS	+.	DNS	DNS	DNS	SNG
Pain (more)	+	+	-/+	DNS		DNS	DNS	I	DNS	+	DNS	DNS
Functional status (lower)	+	+	+	-/+	+	+	+	ſ	DNS	+	ı	+
Job physical demand (higher)	+.	DNS	DNS	DNS	• •		+	DNS	+	+	1	+
Job autonomy or discretion (less)	I	DNS	DŇS	DNS	ı	DNS	+		DNS	DNS	+	+
Type of job (non-managerial, non-professional)	+	+	-/+	ı	• •	•	I	I	B	DNS	+.	+
Job satisfaction	I	DNS	DNS	DNS		DNS	DNS	B	DNS	DNS	DNS	DNS
Household responsibility (less)	ı	DNS	SND	DNS	DNS	SNG	+	I	DNS	DNS	DNS	DNS
Coworker or social support (less)	+	DNS	SNG	DNS	DNS	DNS	+	I .	DNS	DNS	DNS	DNS

The preceding studies addressed the identification of risk factors for leaving employment. Inherent in such studies is an assumption that if risk factors are alleviated, the incidence of work disability may be reduced. While some risk factors are not modifiable, such as age, others may be, such as reducing physical demand of the job or the person's physical capacity to do the work. Improving participation in paid work depends on whether or not the risk factors for work disability are amenable to intervention (Allaire et al., 1996). Therefore, instead of focusing on work disability, the aim of some investigators has been to identify factors associated with successful return to employment after an absence due to arthritis.

Allaire and colleagues (Allaire, Partridge, Andrews, & Liang, 1993) reviewed utilization and effectiveness of the state-federal vocational rehabilitation program in the United States using figures in the national data base for clients served 1977 through 1988. Even though arthritis is the second leading cause of work disability payments in the USA, the proportion of clients with arthritis who used state-federal vocational rehabilitation services was only about 2%, with annual utilization ranging from 1.6% to 2.2% of all clients served. The authors suggested that one possible reason for low utilization was the vocational rehabilitation process itself: it tends to stress lengthy evaluation and work preparation and this approach may not be suitable for workers with arthritis, who (because of their age) may already have a substantive work history and well-developed interests. To evaluate the effectiveness of vocational rehabilitation, they used work status at time of case closure in the years 1977 (n = 250,250), 1982 (n = 176,050), 1985 (n = 193,070) and 1988 (n = 386,240). The proportion of arthritis cases that had returned to work was 62%, which compares favourably to the overall rate of 65% for all cases. However, long term work retention was not studied, so it is unknown if those who returned to work subsequently left the work force or maintained employment.

To examine return to work outcomes among people unemployed due to arthritis and musculoskeletal disorders, Straaton and colleagues (Straaton, Maisiak, Wrigley, & Fine, 1995) documented the occupational status of 4093 subjects in a 5-year prospective study examining the effect of the Alabama state-federal vocational rehabilitation program. A successful outcome was defined as completion of the vocational rehabilitation program,
obtaining and retaining employment for at least 60 days. Of those referred for services, 71% achieved a successful outcome. The strongest factor associated with return to work was lack of disability benefits. Being female and having higher than grade 12 education also correlated with return to work. Because the sample included people with musculoskeletal disorders that heal over time, as well as chronic conditions like RA, it is difficult to generalize the findings to people with RA even though they comprised part of the sample.

However, similar trends were noted in a review of 456 patients with confirmed diagnoses of OA, RA, spondyloarthropathies, juvenile arthritis, lupus or miscellaneous rheumatic conditions who received state-federal vocational rehabilitation services in Alabama during the three year period 1985-88 (Straaton, Harvey, & Maisiak, 1992). A successful outcome was defined as suitable employment for 60 days following the vocational rehabilitation program. The authors reported that the factors most strongly associated with return to work among people with arthritis were physical restoration, retraining, public support and dollars spent. "Physical restoration" included medical and surgical consultation, physical therapy, occupational therapy and provision of orthoses. The partial odds ratio for receiving physical restoration and successful work outcome was 5.47 (95% confidence interval 3.33, 8.98). In the sample studied, 82% did not have medical insurance and therefore did not have access to physicians, physical therapists and occupational therapists except through the vocational rehabilitation process. Because the purposes of surgery, physical therapy and occupational therapy include improving functional status, and because lower functional status was a risk factor for work disability in the studies cited earlier, there seems to be support for suggesting that work outcomes may be improved with access to medical and therapy services.

"Retraining" included the acquisition of new skills through post-secondary education, business school or on-the-job training. The partial odds ratio for the association between receipt of training and successful return to work was 3.43 (95% CI 1.9, 6.2). Public support was the receipt of social security disability benefits or other similar publicly-funded aid. Just over half of those receiving public support returned to work while 68% of those not receiving support returned to work (partial OR .38, confidence interval .22, .66). However, if the

amount of money spent during a person's rehabilitation program exceeded the mean, 75% of the sub-group returned to work compared to 53% of those who had less than the mean amount spent (partial OR 2.15, CI 1.32, 3.50) (Straaton, et al., 1992). There are limitations in interpreting these results, e.g., perhaps people without benefits returned to work out of economic necessity rather than as a result of the vocational rehabilitation services. The study was also limited, like others, by defining successful outcome as 60 days of employment, so the long term benefits (if any) are unknown. This is particularly important for a chronic illness like RA, which is characterized by exacerbations and remissions of symptoms.

To identify barriers to return to work, Straaton and colleagues (Straaton et al., 1996) interviewed a sub-group (n = 218) of the participants from the study cited above (Straaton, et al., 1992). Interviews were scheduled at baseline and 12 months after study entry, and included sociodemographic characteristics, job classification according to the Dictionary of Occupations, physical demands of the job (five classifications according to US Labor criteria), occupational prestige on a 1-100 scale, health status measured by the Sickness Impact Profile (SIP), interpersonal support, and vocational potential as measured by the Preliminary Diagnostic Questionnaire (PDQ). Diagnoses were confirmed by physicians and classified using ICD codes, and the current economic environment was considered by noting the unemployment rates in the subject's county of residence.

At 12 months, two had died (and their data were kept in the not working group), and two had been lost to follow-up. Return-to-work was defined as full-time or part-time employment of more than 20 hours per week, in paid, permanent jobs. Fifty-one subjects (24%) were working at follow up. The diagnoses included 31% back disorders, 19% OA, 14% fractures, 11% RA, 10% fibromyalgia, and 6% lupus. The distribution of pre-illness occupations was 33% clerical/sales, 21% professional/managerial, 16% service, and 10% agricultural/trades. In the multiple regression model, the five significant barriers to return to work were having a diagnosis of RA, receiving disability benefits, reporting pain greater than 5 on a 10 cm visual analog scale, having a diagnosis other than a fracture, and an education level less than high school graduation. Return to work was not associated with the characteristics of the subject's previous job, such as strength requirements of the work or

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occupational prestige (Straaton, et al., 1996). Additionally, return to work was not associated with the local unemployment rates or the length of unemployment.

In a prospective intervention study, Minor and Hewett (1995) investigated the association between physical fitness and work capacity in women with RA in a non-randomized controlled trial. The experimental group (n = 20) participated in three months of supervised group exercise sessions while the control group (n = 22) received no attention other than baseline and follow-up measures. Subjects were assigned based on their proximity to the exercise group meeting place, and were followed for one year. Variables measured included physical fitness (cardiorespiratory function, flexibility, strength and endurance, and body composition); work capacity (Brigham Work Capacity Evaluation with sitting, hand function, lifting, reaching and leg strength items); and disease status (active joint count, pain scale). After three months of exercise, the experimental group had significantly better than controls on these two variables. There were no differences on any other measure.

Minor and Hewett (1995) also estimated the physical level of work, as defined by the Dictionary of Occupational Titles (DOT), that subjects would be capable of doing. To explore variables that might explain capacity to engage in medium level work (DOT level 3), a stepwise logistic regression procedure was used. Only hand dexterity and grip strength were identified as predictors of ability to work at this level. This was an interesting finding, especially given the focus on general fitness, since such programs are unlikely to have an impact on hand function. While it is logical that people with arthritis will have reduced hand function, and that this may limit their ability to do certain work tasks (e.g., keyboard skills, manipulating small objects, maintaining a strong grasp), it would be more logical to expect systemic symptoms such as fatigue to influence work capacity at medium levels. Physical re-conditioning is intended to reduce fatigue and enhance physical capacity, but this association was not demonstrated in the study. In discussing the limitations to their study, the authors suggested that both sample size and inadequate sensitivity of their work capacity measure need to be considered as possible explanations for their inability to demonstrate a significant relationship between improved physical capacity and work capacity.

1.5 Arthritis and Unpaid Work

Participation in unpaid work by adults with arthritis has received considerably less attention than the effect of arthritis on paid work, and the research that has been published focuses largely on women and household work.

Reisine and colleagues (Reisine, Goodenow, & Grady, 1987) interviewed 142 women with RA, aged 18 to 65 years, recruited through a university hospital arthritis clinic and five private rheumatology practices. Women were considered "homemakers" if they were living with a husband and/or children at the time of disease onset; 45% of the sample were also employed outside the home. Homemaking was considered to have two dimensions, instrumental and nurturant. Instrumental functions were represented by five tasks: cooking, cleaning, laundry, shopping, and managing finances. Nurturant functions were represented by childcare, and the 'mental hygiene' needs of the family, specifically listening to family members, making arrangements or appointments, and maintaining ties with friends and relatives. Nurturant functions also included taking care of sick people, teaching others, engaging in hobbies, and interest in and amount of sexual activity. For all tasks, respondents were asked if their RA had changed the amount of time they spent doing the activity (on a 5point scale from much less time now, through no change, to much more time now). For selected tasks (cooking, cleaning, shopping, and childcare) more detailed information was collected, including the proportion of the task done at disease onset versus the proportion done at the time of interview, and perceived satisfaction with ability to do the task. These additional questions were limited to selected items to keep the interview under 90 minutes. The interview also included basic demographic information and the HAQ.

The mean age of the group was 52 years (SD = 9 years). The women had an average of four people living in their household (SD = 1.7) and 80% of them were married. They were well-educated, averaging 13 years of school (SD = 2.3). The mean HAQ score of 0.60 suggested they experienced mild to moderate functional impairment. Overall, 86% of the sample reported at least one role limitation. More than half the sample reported limitations in cleaning (73%), laundry (65%), and shopping (61%), while less than half reported limitations with cooking (42%) and managing finances (16%). Of those who had pre-adolescent

children (n = 50), 29% reported limitations in caring for them. Limitations in the other nurturant functions ranged from 16% of the sample reporting problems with listening to 42% reporting problems with making arrangements and maintaining ties with others. In general, those reporting limitations were significantly less satisfied with their ability to perform a task than those not reporting limitations for the same task. A comparison between full-time homemakers (n = 78) and those who were also employed outside the home (n = 64) demonstrated just three significant differences. A larger proportion of full-time homemakers reported limitations in cooking (51% compared to 33%, p < .05) and sexual activity (63% compared to 40%, p < .01). They also reported lower functional status, with a mean HAQ score of 0.73 compared to 0.44 (p < .001) (Reisine et al., 1987).

This descriptive study suggested that RA does impact on household work performance. However, it was limited by recall bias because the questions asked whether or not the respondent thought that arthritis had changed the time spent performing selected activities, and it had been about 10 years since the onset of arthritis. Time spent doing household activities may change over time, whether or not an illness is present, because the composition of the household changes (children grow and take on chores, or leave home) or homemaking standards are modified (less priority given to home baking, for example).

To try and account for these limitations, Allaire and colleagues conducted a similar study, this time adding a non-disabled comparison group (Allaire, Meenan, & Anderson, 1991). They designed a mail survey instead of an interview, but borrowed several questions from Reisine and colleagues' (1987) study described above. Letters of invitation were sent to 496 women with RA with known addresses among the patient files of 16 rheumatologists across the USA. In addition to screening for eligibility criteria (female, married or having children at time of disease onset, less than 65 years of age, and no other chronic illness), women were asked to provide the name and address of a friend or neighbour who met the same criteria, exclusive of the RA diagnosis. The final sample consisted of 142 women with RA and 58 non-disabled women, each of whom completed a three-part questionnaire.

The questionnaire included four measures of household work performance: (a) current number of hours spent on household tasks; (b) current proportion of the household

work performed by the respondent (relative to all household work done by all members of the household plus paid help if applicable); (c) change in hours since the onset of arthritis (or about 10 years ago in the case of controls); and (d) change in proportion of time spent on household tasks. The tasks were cooking, cleaning, laundry, shopping/errands (borrowed from Reisine et al., 1987), plus after meal clean-up. The nurturant tasks used by Reisine and colleagues (1987) were combined into a single question asking about time spent nurturing children and making arrangements for others ('taking care of others'). The questionnaire was pre-tested with a convenience sample of 15, and test-retest reliability was assessed by randomly selecting 25 of the study respondents to complete the survey a second time two months after the first time. The intraclass correlation coefficients showed test-retest reliability ranged from 0.72 to 0.93 depending on the item.

The second section included the HAQ as a measure of functional status, and selected scales from the Arthritis Impact Measurement Scales (AIMS) (Meenan, Gertman, & Mason, 1980) to estimate pain, perception of general health, and anxiety/depression. The final section asked about family characteristics such as number and ages of children, income, and husband's level of education and income; as well as demographic characteristics of the respondent, including age, education level, ethnic background, employment status, work hours, and salary.

In the analysis, the RA group was sub-divided into those with mild disease (HAQ scores ≤ 1 , n = 84) and those with moderate/severe disease (HAQ scores > 1, n = 58). Comparison subjects remained as one group. The three groups differed in age, so all subsequent comparisons were age-adjusted. The groups did not differ in the amount of time currently spent on household work, neither by individual task nor the total time spent on all six tasks studied. However, women with more severe RA reported doing a significantly lower proportion of the total household work in their household than either the mild RA or non-disabled groups. All three groups reported spending less time doing household work now compared to time of disease onset or 10 years ago. This is an important finding suggesting that factors other than chronic illness may reduce time spent on household work (children leaving home, for example). Women with mild RA reported a greater decrease in

time spent shopping than did women without RA. Women with more severe disease reported significantly greater reductions in time spent on all of the tasks except for taking care of others, and they reported that their family members had assumed a greater proportion of the household work compared to both of the other two groups.

In regression analyses, the authors explored the relative contributions of health status, family, and personal factors to household work disability, as measured by each of their four dependent variables. Better functional status was significantly associated with more household work performed in three of the four models, otherwise, the best predictor variables differed for each of the four dependent variables. More depression was associated with increases in both time spent and proportion of household work done. Having children at home increased the amount of time spent on household work, and being employed outside the home decreased the amount of time spent on household work, as did being a college graduate.

Using a cross-sectional interview with 194 women with RA, Goodenow and colleagues (Goodenow, Reisine, & Grady, 1990) investigated relationships among social support, health status, depression, and home and family role dysfunction. Home and family role dysfunction was evaluated by asking respondents if RA had limited their performance of 13 different activities: cooking, cleaning, shopping, laundry, paying bills, child care, listening to others, maintaining family ties, making arrangements for family members, teaching others, taking care of sick people, sexual activities and pursuing hobbies. All "yes" responses were summed, for a possible impact score ranging from 0 to 13. Social support, and equity in giving/receiving support. Health status was measured with the HAQ, and depression was measured using the Center for Epidemiological Studies-Depression Scale (CES-D) (Radloff, 1977).

Respondents were on average 51 years of age, with mean disease duration of 11 years, and most were married (73%). Hierarchical multiple linear regression showed that home and family role dysfunction was associated with lower functional status and lower quality of social support (as measured by the Quality of Social Support Scale designed for

the study). These same two variables were the only significant predictors of depression, as well. Disease severity, social network, and social equity were not associated with either outcome. Thus, the studies led by Goodenow and Allaire both found lower functional status to be a predictor of dysfunction in household work. The other explanatory variables were unique to each study, so no other trends could be identified.

Unpaid work was part of the MacKinnon study already introduced in the previous section on arthritis and paid work (MacKinnon, 1992; MacKinnon et al., 1994). Whereas the above studies of household work were exclusive to women with RA, MacKinnon's sample included both men and women. Participants in the case-control study completed 7-day diaries listing all of their daily occupations, and were interviewed for demographic and health status variables. The mean age in both groups was 49 years, and the RA group reported a mean disease duration of 11 years. Twenty-five percent of the sample was male, however, the reported results remained in aggregate form and did not explore gender differences. Compared to controls (n = 124), the RA group (n = 128) spent significantly less time in child care (1.7 hours/week compared to 3.6 hours/week, p < .05), but differences in household/vard work and shopping were not statistically significant. Pearson correlation coefficients were reported for depression, anxiety, life satisfaction, functional limitations, number of involved joints, and four aspects of pain relative to each work category (market work, household/yard work, child care, shopping). Time spent on household/yard work was significantly and positively correlated with current pain level (r = .16). Psychosocial variables, functional limitations, number of involved joints, severity of pain, restriction of pain and pain frequency were not. The only variable associated with hours of child care was pain frequency (r =-.18). None of the associations with shopping were statistically significant. The absence of significant correlations between psychosocial or functional variables and occupational profiles led the authors to speculate on alternative hypotheses, and they proposed mastery, self-esteem and social support as potential variables for future study.

In summary, what are the lessons learned from the arthritis literature related to paid and unpaid work? Several factors appear to influence engagement in paid and unpaid work. There is evidence indicating that as pain and functional limitations increase, work decreases.

This is not a profound finding, it smacks of common sense. However, pain and functional status do not fully account for variations in paid and unpaid work by adults with RA. Work outcomes seem to be mediated by additional factors, such as demands of the work or environmental supports. For example, Allaire and colleagues (1991) noted that children increased the time spent on household work, but not the proportion of household work done by the women of the household. More people simply created more work for all. And Goodenow and colleagues (1990) found it was the quality of social support, more than the amount of support, that was associated with fewer limitations in home and family roles. Future research may best be guided by a conceptual framework that considers factors from several domains, including characteristics of the individual, the environment, and the work.

1.6 Conceptual Framework

The review of previous studies indicates that participation in paid and unpaid work is likely influenced by multiple factors. It is not feasible to study every hypothesized contributing factor in a single study. The Person-Environment-Occupation (PEO) conceptual model (Law et al., 1996; Strong et al., 1999) was adopted as a framework to organize and help make decisions about which factors to include in the study. The PEO model is one of several person-environment models cited in the literature related to human ecology; it was selected because it adds the dimension of occupation to the person-environment relationship.

In this model, the dynamic relationships among factors from three areas determine one's capacity to engage in occupation: characteristics of the *person* (individual skills and characteristics), the *environment* (physical and social supports and barriers), and the *occupation* (demands of the tasks involved). Figure 1 provides a schematic representation of the model, consisting of three inter-related circles. The overlapping area is labeled occupational performance, or the person's ability to do the things he or she needs and wants to do.



Figure 1. Schematic of the Person-Environment-Occupation Model. From: Law, et al., 1996.

The schematic represents a cross-sectional view of the transactional relationships among person, environment and occupation for a given event or one point in time. When there is a poor fit among characteristics of the person, environment and occupation, occupational performance suffers; occupational performance is enhanced when there is greater overlap among the three circles, or when characteristics of the person, environment and occupation are complimentary.

The following concepts, defined by the authors of the PEO model, help to explain the model: The person is a unique being who brings a set of attributes and life experiences to bear on the transaction labeled occupational performance. This includes personality, cultural beliefs, motor, sensory and cognitive abilities, general health, and a set of unique skills both learned and innate. The environment is the context in which the person functions, and refers to the cultural, socio-economic, institutional, physical and social influences that exist outside of the individual. Activity, task and occupation are concepts nested within each other: (a) an activity is a basic unit or act, such as writing; (b) a task is a set of purposeful activities, such as writing a thesis; and (c) an occupation is a group of self-directed tasks and activities, such as completing a doctoral degree (which involves thesis-writing, among other tasks). Occupational performance is the outcome of the transaction of person, environment and occupation. The transaction will be influenced by time patterns and rhythms that are associated with the person's routines over a day, week, month or lifespan, and this is referred to as the temporal aspects of the model. The PEO model assumes that person, environment and occupation "interact continually across time and space in ways that increase or decrease their congruence. The closer their overlap or fit, the more harmoniously they are assumed to be interacting. The outcome of greater compatibility is therefore represented as more optimal occupational performance" (p. 17, Law, et al., 1996).

The PEO model is a useful framework for the present study because participation in paid and unpaid work depends on the fit between the person, the environment in which they perform, and the demands of the work. To study factors associated with participation in paid and unpaid work without considering at least some factors from each of the three spheres would surely miss an important piece of the puzzle that potentially explains level of

participation in work. The PEO model is adapted for the present study by labeling the occupational performance transaction (the triangular overlap of person, environment and occupation) as participation in paid and unpaid work. As the fit improves, the area of overlap increases, and the individual achieves optimal participation in paid and unpaid work activities. Figure 2 illustrates the adapted model, with sample characteristics of the person, the environment, and the occupation, which could be selected for study.



Figure 2. Person-Environment-Occupation Model Applied to Investigating Participation in Paid and Unpaid Work.

1.7 Research Questions

The purpose of the study was to investigate factors associated with participation in paid and unpaid work. The objectives and their associated questions were as follows:

- 1. To consult with people who have RA, health care providers and academics to develop an inventory of what is considered productive work and the factors that should be considered when investigating participation in such work. What do "experts" think should be studied?
- 2. To develop and validate a measure of participation in paid and unpaid work that is inclusive of occupations related to employment, household work, caregiving, studying and other forms of paid and unpaid work that might be identified in objective 1. How should participation be measured?
- 3. To field-test a mail-survey designed to measure participation in paid and unpaid work and the factors associated with levels of participation or productivity. Will the survey be feasible and generate responses that can be analyzed to address the objectives?
- 4. To conduct a cross-sectional survey to identify factors associated with participation in paid and unpaid work among adults with RA. This was the main objective, and it generated several questions:
 - To what extent are people with RA participating in paid and unpaid work?
 - Does work participation vary with gender, age, disease status or functional status?
 - How does work participation by adults with RA compare to the general population?
 - Are people with RA satisfied with their work?
 - Are people limited by their arthritis, and if so, how does their work differ from those not reporting work limitation secondary to RA?
 - What factors are associated with participation in paid and unpaid work, and what multivariable model best predicts work participation?

Chapter II Survey Development

The study was conducted in two parts. Part one consisted of survey development, including consultation with content experts (people with RA, health care providers and academics), re-visiting the literature, and field-testing survey items. Part two, a cross-sectional study, consisted of a mailed survey to identify factors associated with participation in paid and unpaid work. Ethical approval for both the developmental phase and main survey was obtained through the University of British Columbia's Behavioural Ethics Research Board (certificate B-980506). This chapter describes the procedures and results of part one: survey development. The method for the cross-sectional study follows in Chapter 3.

The survey development was an iterative process involving consultation with content experts first, followed by pre-testing selected questionnaire items, and concluding with a field test of the penultimate draft of the survey to be used in the cross-sectional study. The general procedures for developing a questionnaire described by Aday (1996), Streiner and Norman (1995), and Sudman and Bradburn (1983), guided the development process. The purpose was to design a self-administered mail survey including a quantitative evaluation of participation in paid and unpaid work and potential explanatory variables. It was intended that survey items be relevant to adults with arthritis and the health care providers who work with them, therefore personal consultation was required. There was no intent to "re-invent the wheel" if adequate items existed in other scales or instruments. Because the review of literature suggested many scales for potential explanatory variables, the major thrust of the consultation process was to determine an appropriate outcome measure for paid and unpaid work. The secondary aim was to identify the most salient potential explanatory variables to be included in the survey, because it would not be feasible to include all possible variables.

2.1 Consultation Procedures

Potential survey items were generated in consultation with people with arthritis, clinical experts and scholars with a non-clinical perspective on work and productivity. Two occupational therapists and one social worker at the Mary Pack Arthritis Program referred adults with RA to participate in small group discussions or interviews. Clinical experts and scholars were identified informally through the investigator's collegial network, and consulted via personal interview, telephone conversation, and e-mail.

Discussion groups and interviews with RA participants were loosely structured using the following four key questions:

- 1. What aspects of paid and unpaid work are important to study?
- 2. How should paid and unpaid work be measured?
- 3. What factors influence people's ability to do paid and unpaid work? (Where necessary, examples were given to clarify the question: Things like your health, or support from other people at work or home, or other factors related to either the person or the work.)
- 4. How should questionnaires be designed so they are easy to complete? (Or, encourage you to respond to them).

Individuals asked for clarification of ideas when necessary, and the relative strengths and limitations of suggestions and ideas were also discussed. The investigator recorded key comments during all sessions. Consultation with health professionals and scholars was guided by the first two questions about studying and measuring paid and unpaid work.

2.2 Consultation Results

Eighteen adults with RA participated in discussion groups and interviews: there were three small group discussions (n = 4, n = 6 and n = 4) and 4 individual interviews (with participants unable to attend the small groups). Signed, informed consent was obtained from each participant (see Appendix 1). They ranged in age from 30 to 60 years, and included people who were currently employed as well as some unemployed. All were engaged in unpaid work. There were 7 men and 11 women, some single, some married, some with children at home. In short, although this was a convenience sample, the participants represented several characteristics of the target population for the cross-sectional study. Professional consultations occurred with two occupational therapists, one social worker, one vocational rehabilitation counselor, one health economist, and one commerce professor.

Notes recorded during the sessions are in Appendix 2. Respondents recommended that the study focus not only on time spent working, but also consider whether or not one is working as much as one wants to work, and satisfaction with work achievements. These recommendations provided guidance for the selection of outcome variables for the survey. Additional topics for study included arthritis symptoms (such as pain and fatigue), ability to cope with arthritis symptoms, physical health, mental or emotional health, support available from family, friends or co-workers, environmental barriers or supports (such as a workplace without stairs, transportation or adapted work stations), and the type of work (including the physical demands of the work tasks or how interesting the work was to the worker). These latter factors provided guidance for selecting potential explanatory variables for the survey.

Health professional/scholar respondents suggested that time spent working captured one aspect of participation in paid and unpaid work. There was concern that one limitation to using hours of work as an outcome measure was that it did not account for people performing the same work at a slower pace than they would without a disability. A second limitation was that hours of work might lead one to assume that "more hours" is synonymous with being "more productive" and would not account for individual choices, for example, choosing to work part-time. It was noted that participation in paid work tended to be measured by the hours spent in the labour market, and the market value of the work. Using this approach, market value of unpaid work could be assessed by identifying the cost of unpaid work if a suitably qualified person needed to be hired to do the work. (For example, assigning a value to cooking hours by calculating the cost of hiring a cook to do the work). No one was aware of a specific measure to evaluate participation in work activities. There was general agreement that recording time spent working would be a starting point for measuring participation in paid and unpaid work, and that people's satisfaction with their level of participation would also be a useful indicator.

With respect to ways to encourage questionnaire participation, patient respondents offered practical suggestions: large font, plenty of white space, and close-ended items that could be quickly checked off. While a large number of pages may be daunting to some, they indicated that it only took a page or two to determine how quick and easy a survey might be to complete. Therefore, a large number of pages (e.g., more than 5 to 10) was not a drawback if the questions were clear and quickly answered.

An informal consultation with RA participants occurred to evaluate pens for completing the questionnaire. Since RA affects the joints of the hands, it was anticipated that some people may have difficulty responding in writing. Provision of a pen was considered a small incentive to make it convenient to participate. Several commercially available "easygrip" pens were reviewed, and two were presented to small group participants. They unanimously identified one as preferable (because the ink flowed easily and not much pressure was required to write), and this pen was provided to all pre-test, field test and main survey participants.

2.3 <u>Pre-Test of Selected Survey Items</u>

A list of potential variables for study was generated (see initial list in Appendix 3), and additional literature was reviewed to select ways of measuring each variable. Where possible, well-established instruments that had been used in studies of people with arthritis were identified. In some cases, however, either no instrument existed or it had not previously been used with similar populations. For these latter variables, instruments and items were selected or adapted for pre-testing. The pre-test (see Appendix 4) was sent to 10 RA volunteers who participated in the small group consultations and had agreed to read sample items. The packet mailed to them consisted of questions about participation in paid and unpaid work adapted from the interview guide used in Statistics Canada General Social Survey (GSS) (Frederick, 1995), a work satisfaction question adapted from the Canadian Occupational Performance Measure (COPM), (Law et al., 1994), work characteristic items from Karasek's Job Content Questionnaire (JCQ), (Karasek, 1985), and the Occupational

Questionnaire (OQ), (Smith, Kielhofner, & Watts, 1986). Questions about commuting to work or run errands, based on those used by Allaire and colleagues (Allaire et al., 1996) were also included. Additionally, the packet contained a short list of questions about the survey items, in order to identify confusing, difficult, and sensitive or intrusive items. These items were pre-tested for the following reasons:

- a) The GSS is an instrument used to collect time-use data from thousands of Canadians over the age of 15, and includes items inquiring about time spent in paid and unpaid work activities. It has been used in several population-based studies, most recently in 1998. Thus, there are data available from the general population to compare with similar data collected from RA subjects. However, the GSS is a telephone interview, so it was necessary to adapt the questions slightly and test their feasibility for use in a mail survey with representatives of the intended population for the current study.
- b) The Karasek JCQ has been used in both population health and clinical studies of adults to measure characteristics of paid work (Karasek et al., 1998). Several of the subscales captured aspects of work that had been suggested by the RA consultants and the RA work disability literature, such as physical demand of the work, support from co-workers, and decision authority (job autonomy). It had not previously been used to measure characteristics of unpaid work, so it was necessary to determine if it would be feasible for this broader purpose, and with the RA population. The items were adapted by changing the phrase "my job" to "my work" to be consistent with the definition of paid and unpaid work provided to survey respondents.
- c) The OQ is a 24-hour diary in which respondents record their main activity for each half-hour time slot during the day, and then answer four questions about the activity. It is an alternative format for measuring participation in paid and unpaid work, but it is more unwieldy than the GSS questions. The intent was to compare the data derived from the two sources, and to determine if the diary could be used for verifying the responses to the GSS questions about paid and unpaid work.

d) The commuting questions had been used in only one prior study, and had not been applied to unpaid workers. The work satisfaction question had been used extensively in interviews for rating specific problems in occupational performance, but not in a written, self-report format for rating the construct of paid and unpaid work.

2.4 Pre-Test Results

Nine of the 10 volunteers completed the pre-test packet. All applicable items were answered by each respondent, and the answers appeared appropriate to the question asked (e.g., if they were asked to estimate hours of work, a numerical answer was provided; if asked to check the best response, one response was checked). People who did not engage in a specific form of work, e.g., caregiving, checked "no" to the screening item and left the number of hours blank. People who worked without supervision did not respond to the JCQ items regarding supervisors.

Respondents did not identify any items as particularly insensitive, intrusive or irrelevant. Most feedback included ways to clarify instructions or a particular item.

Some stated that estimating hours of child care (caregiving hours) was difficult because it is an ongoing, 24-hour a day job. However, all of those participating provided a response to this question that appeared to reflect direct caregiving (time spent with a child in a specific activity, such as taking the child to school, helping with homework, bathing the child, or reading to the child). None of the 9 pre-test respondents were providing care to an ill or elderly family member, but it was noted that caregiving was broadly defined to include more than child care, if applicable to individual respondents.

Responses to question one in the Occupational Questionnaire were inconsistent with regard to unpaid work. After listing the main activity for each half hour in the day, question one asked respondents to classify each activity as work, a daily living task, recreation or rest.

Despite the definition of work including both paid and unpaid work, some respondents identified only paid work as a "work" activity, and identified unpaid work as a daily living task. Therefore, the response choices for question one were revised for the field test to paid work, unpaid work, personal/self care, recreation and rest.

With respect to the work characteristics items from the JCQ, it was suggested that they be included twice, once for paid work and once for unpaid work. Therefore, in preparation for the field test, this section of the survey was revised to request that respondents complete the JCQ items first for their main form of work (the occupation written down in response to a previous item asking "What do you consider to be your main occupation?"), and gave the option of completing the JCQ items a second time if they considered themselves to have "two jobs," such as a mother and a paid employee.

The varied responses to the item "what do you consider to be your main occupation?" suggested that additional clarification would be helpful in classifying work, and a part (b) was added: "Which of the following best describes this occupation?" Response choices were household work, full-time employee, part-time employee, self-employed, student, volunteer, retired, and other. Respondents stated that it took 15 to 30 minutes to complete the pre-test packet, which helped estimate the time required for the field tested version.

2.5 Field Test Procedures

Using the results of the pre-test together with advice from the initial consultation process, revised literature search and guided by the Person-Environment-Occupation (PEO) conceptual model cited earlier, a draft survey was developed. It contained questions measuring participation in paid and unpaid work, work limitation, satisfaction with work, several potential explanatory variables, and demographic characteristics. The layout followed as much as possible the advice from clients with arthritis who participated in the group discussions and interviews. Instructions were revised in accordance with suggestions from the pre-test. A draft survey was reviewed by two colleagues for clarity of instructions,

ease of reading and overall format. Items from standardized instruments were left intact (with the single exception of changing "my job" to "my work" within applicable items from the Job Content Questionnaire), but formatting changes were made based on advice from the two proofreaders.

The purpose of the field test was to assess the utility of the survey and reminder process, estimate response rates, and evaluate the reliability and validity of the outcome measures. Utility refers to the practical aspects of conducting the survey, e.g., Will patients complete the questionnaire? Will the responses be suitable for analysis? Will the reminder notes and timing of them be adequate to maximize returns? The outcome measures assessed were hours of paid and unpaid work, work limitations attributed to RA, and work satisfaction.

The draft survey was field-tested with a convenience sample of adults with RA from two clinics at The Mary Pack Arthritis Centre. Those attending the "hydoxychloroquin clinic" (a first-line medication) represented patients with mild disease, and those attending the "cyclosporin clinic" (a more aggressive medication with greater risk of side effects) represented patients with more severe disease. Because the purpose of the present study was related to work, patients older than 65 were excluded. Twenty-one eligible names and addresses were identified in clinic records, 10 from the hydroxychloroquin clinic and 11 from the cyclosporin clinic. A cover letter (Appendix 5), draft survey and Occupational Questionnaire were mailed to all 21 patients. A reminder (Appendix 6) was sent to nonresponders after two weeks, and after four weeks, if necessary. The survey was sent a second time to those who responded to the first survey, to obtain information for estimating testretest reliability of items related to participation in paid and unpaid work. By selecting patients with mild and severe disease to participate, it was anticipated that the discriminant validity of the outcome measures could be assessed. Such assessment presumes that there are differences in work hours between those with mild and severe forms of RA. The Occupational Questionnaire was included as a measure of concurrent validity for the main outcome measure of hours spent in paid and unpaid work.

2.6 Field Test Results

Of the 21 surveys mailed, two were returned by the post office due to incorrect addresses, and five were returned by patients with notes declining to participate. Two of the refusals stated that they were applying for disability benefits and were concerned that participation in a survey about work would jeopardize their applications. Two patients did not respond to the survey or the reminders, so refusal to participate was inferred from the lack of response. Twelve patients returned completed surveys, six from the hydroxychloroquin clinic and six from the cyclosporin clinic (response rate 12/19, 63%).

Participant characteristics. There were 10 women and 2 men (83% female), ranging in age from 39 to 65 years (mean = 51.7). The average duration of their RA was 16 years (ranging from 7 to 30 years). As expected given the recruitment method, they represented mild to severe forms of the disease, with Health Assessment Questionnaire Disability Scale (HAQ) scores ranging from 0.50 (mild impairment in activities of daily living) to 2.13 (moderate to severe impairment). The mean HAQ score for this sample was 1.07.

<u>Hours of work</u>. The main outcome measure in the survey was hours of paid and unpaid work reported in the week prior to survey completion. Average hours of work are listed in Table 3. Participants reported a full range of work hours, from no paid hours for six participants who identified themselves as retired or no longer employed, to 60 hours for a participant employed full-time as a journalist. Their unpaid work hours ranged from 4 hours for one individual with severe disease reporting those few hours of household work, to 63 hours for an individual with major responsibility for household management in a household of 3 adults, and 54 hours for a single mom with two children under 18.

Table 3. Hours Worked Last Week by Field-test Subjects,	n = 12.
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	Paid Work	Unpaid Work	Total Work
Mean	18.75	23.63	42.38
Range	0 - 60	4 - 63	4 - 82

<u>Work Limitations</u>. One secondary outcome measure was whether or not respondents were limited in their ability to work as a result of their arthritis. The question asked "Do you work as many hours per week as you would like?" to which they could respond yes; no, I work more than I want to; or no, I work less than I want to. If the response was no, respondents were asked to indicate the reason. Six respondents (50%) reported working fewer hours than they wanted to because of their arthritis: three with mild RA and three with severe RA. Of the six respondents not limited by their RA, three reported working more hours than they wanted to, and three reported being satisfied with the number of hours they worked.

<u>Work Satisfaction</u>. The other secondary outcome measure tested in the field trial was satisfaction with ability to perform work activities, on a 1 to 10 scale (1 = not at all satisfied, 10 = very satisfied). The question asked "On a scale of 1 to 10, how satisfied are you in your ability to perform your main work activity?" Respondents used the full range of the scale, from 1 to 10, with an average work satisfaction rating of 5.83, and median rating of 7.

<u>Reliability</u>. The survey was completed twice to estimate test-retest reliability, with time 2 approximately two weeks after time 1. The intraclass correlation coefficient (ICC) was used to assess reliability for the variables paid work hours, unpaid work hours, total work hours (the sum of paid and unpaid work), and work satisfaction. Percent agreement was used to assess reliability of the categorical work limitation variable. The coefficients are reported in Table 4.

	ICC	95% confidence interval
paid work hours	.99	.97 – 1.0
unpaid work hours	.90	.64 – .97
total work hours	.96	.87 – .99
work satisfaction	.97	.85 – .99

Table 4.	Fest-retest	Reliability	for Outcome	Variables
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Given that paid work hours are generally stable, because they tend to be assigned by an employer in accordance with a contract or work schedule, a high correlation was a reasonable expectation for paid work. Unpaid work may be more discretionary, subject to greater fluctuations and less reliable recall, but the correlation of .90 suggested very good stability in the self-report of unpaid work hours. The secondary outcome measure of work satisfaction was measured using a 10-point scale. The ICC of .97 suggested that this, too, was a stable measure in the sample tested.

The secondary outcome measure of work limitation attributed to arthritis is a simple yes/no response scale. Responses to this question at time 1 and time 2 were compared, and percent agreement calculated. There was 83% agreement. Two participants gave a different response at time 2 compared to time 1. Specifically, one reported no limitations at time 1 (worked as much as she wanted to) and reported limitations at time 2 (working less than she wanted to), and the other subject reported the reverse. There was no indication in the questionnaire responses regarding a reason for these changes. However, it is reasonable to expect some respondents to have differing responses if they were experiencing an exacerbation of their arthritis during time 1 or time 2, but not both. While this is plausible, it may not be the only explanation for the difference. The level of agreement was considered reasonable, and the question was not changed.

<u>Validity</u>. The primary outcome measures of hours of paid and unpaid work rely on self-report and recall of the activities during the week prior to the survey. To assess the extent to which recall would match more intensive recording of work activities, participants completed the Occupational Questionnaire, which includes a list of the primary activity in each half-hour of the day. The OQ has adequate test-retest reliability coefficients in previous studies of both college age and older adults, ranging from .68 to .87, and has demonstrated criterion validity of 84 to 92 percent agreement with results of a household work diary (McColl & Pollock, 2001; Smith et al., 1986). It also discriminates between adults reporting high and low life satisfaction. The National Institutes of Health Activity Record, an expanded version of the OQ, has been validated in a study of adults with RA (Gerber & Furst, 1992). In general, diaries have been more accurate in documenting time use than

asking respondents to estimate hours (Robinson & Gershuny, 1994), but they carry a greater respondent burden. Therefore, a diary was selected as the criterion validity measure against which to compare the estimated responses to time spent in paid and unpaid work.

The OQ was completed for a typical day, selected by the respondent. The number of paid and unpaid work hours completed in a day should be associated with the number of paid and unpaid work hours in a week, since 24 hours is simply a subset of 7 days. The association between the OQ and hours of paid and unpaid work "last week" reported at time one was used as an estimate of concurrent validity. Pearson's r was .96 (p < .001) for paid work and .75 (p < .01) for unpaid work. The relatively high correlations between the diary and recalled hours of work suggested that the GSS questions about hours worked last week provided valid estimates.

Although the original intent for recruiting participants with mild and moderate disease was to also assess discriminant validity, the sample of 12 was inadequate for this purpose. The six subjects with severe disease worked fewer hours (mean total work = 32 hours, SD = 25) than the six subjects with mild disease (mean total work = 53 hours, SD = 34) but, with so few subjects per group, there was inadequate power to detect a statistically significant difference. In a t-test for independent means, the mean difference of 21 hours had a significance level of p = .25. The 95% confidence interval of the difference was -5.8 to 50.8. These results suggest that a future study assessing discriminant validity would require a sample size of 20 to detect a similar difference based on the variance observed here and $\alpha = .05$ and $\beta = .8$.

<u>Comprehensiveness</u>. Finally, in comments to an open-ended question at the end of the survey, four respondents indicated that support from family or friends was an important part of how they managed the ups and downs of living and working with RA. This served as a useful reminder that social support had been mentioned in the discussion groups, and it had been an oversight not to include a specific measure of social support as a potentially important explanatory factor in the pre-test and field test. However, at 18 pages and an

estimated hour or more to complete, the potential response burden for the survey was judged to be near maximum. Therefore, in seeking a social support measure, brevity was a primary factor in addition to the usual criteria of selecting relevant, reliable, and valid measures. Although many comprehensive instruments were available in the literature, the choice was limited to those with 20 or fewer items. The Multi-dimensional Scale of Perceived Social Support (MSPSS) (Zimet, Dahlem, Zimet, & Farley, 1988), a 12-item scale assessing support available from a significant other, family and friends, was added to the field test version of the survey.

The utility of the field test version of the survey and the reliability and validity estimates of the outcome measures were judged to be adequate to proceed to the main crosssectional study. The final version was sent for printing and assembly into a 20-page booklet (19 pages with a blank back cover). It was also forwarded to the Behavioral Ethics Research Board in compliance with the two-phase ethical review required of research projects that involved questionnaire development.

2.7 Variables Selected for the Final Survey

The outcome and potential explanatory variables selected for the final survey are listed in Figure 3. A complete description of how they were measured can be found in the section on Instrumentation in Chapter 3.



Figure 3. Final Variables Selected for Study, Illustrated Using the Person-Environment-Occupation Framework.

Numbers in brackets indicate how many subscales address that topic. For example, the variable social support has 3 measures: social support from significant other, family, and friends. Note: Role balance is a synonym for occupational balance.

Chapter III Method

This chapter describes the method for the main cross-sectional survey. The survey was conducted to address the key research objective of exploring factors associated with participation in paid and unpaid work.

3.1 Participant Eligibility and Recruitment

Inclusion criteria and their rationale were as follows:

- 1. Adults ≤ 65 years of age. The target population is working adults, so a cap was set at the conventional age of retirement.
- 2. Diagnosis of RA, determined by the referring rheumatologist. The target population was adults with RA, and rheumatologists are familiar with standard diagnostic criteria.
- 3. Able to read and write English. The survey was written in English.

Potential participants were identified through rheumatologists in private practice in the Lower Mainland. Sixteen rheumatologists were identified, and originally 12 indicated interest in supporting the study. At the time recruitment began, 2 had stopped practicing due to illness and 2 stated they did not have patients meeting the inclusion criteria. Two physicians chose to hand out invitations to patients seen in their offices. For the remaining 6 physicians, letters of invitation were sent from the rheumatologist to all eligible patients for whom they had current records. "Current" was defined as a patient who had been seen at least once in the past two to three years, depending on how the individual office separated its patient files into active and archived files. Two physicians in a shared practice had a single filing system for patients, thus the response rates reported later are traced for 5 practices.

Letters of invitation briefly explained the project (see Appendix 7) and provided a reply form and stamped envelope addressed to the investigator. Patients who released their name and address to the investigator were considered registered for the study. Patients not willing to release their name and address were invited to provide basic demographic

information for comparison with respondents. Invitations returned to sender were tallied in order to calculate accurate response rates.

3.2 Procedures

A cover letter explaining the purpose of the study and consent details, together with the survey, 24-hour activity diary (OQ), stamped return envelope and pen were mailed to all subjects who registered for the study (see Appendix 8). Envelopes were coded to facilitate the sending of reminder cards at approximately 2 and 4 weeks after initial mail-out (Appendix 9). A final reminder telephone call was made to those registrants who had not returned the survey after two months. This process was intended to reduce unnecessary mail to those who responded promptly, maximize returns, and minimize response bias (Aday, 1996; Streiner & Norman, 1995). Returned surveys were separated from their envelopes upon receipt to maintain anonymity of respondents.

Sample size calculations were considered from the perspective of a study using multivariable regression equations as the main form of statistical analysis. For linear regression analyses, the recommended sample size is 5 to 10 times the number of variables to be entered in the equation (Kleinbaum, Kupper, Muller, & Nizam, 1998; Norman & Streiner, 1994). The maximum number of candidate independent variables for any of the proposed analyses was 30, suggesting 150-300 as an adequate sample size. In the hierarchical approach planned (see data analysis section), the number of independent variables considered was lower (up to 14), suggesting a minimum sample size in the range of 70-140.

3.3 Instrumentation

The details of the survey development were described in Chapter 2. The list of outcome and explanatory variables, their definitions, and possible score ranges are listed in Tables 5 and 6 (placed at the end of this section). Re-coding and scoring formulae for all scales used in the survey are in Appendix 10. The instruments contributing to the list of variables include the following:

The modified *Health Assessment Questionnaire* (HAQ) disability index is an 8-item scale widely used in rheumatology research to measure functional status (Pincus, Summey, Soraci, Wallston, & Hummon, 1983). It is an abbreviated version of the original 20-item HAQ (Fries et al., 1982; McDowell & Newell, 1996). Respondents report their level of difficulty doing the activities of daily living specified in each item on a 4-point scale (0 = no difficulty, 3 = cannot perform this task). The scale score is the mean of the 8 items. The test-retest reliability at one month for the modified HAQ was 0.91 in a sample of 30 patients with rheumatological conditions (Pincus et al., 1983). It also correlated with other functional indicators such as grip strength and walking time, with direct observations of performance, and with another functional scale, the AIMS (McDowell & Newell, 1996). Its reliability and validity has been sufficiently well-established that the HAQ has been described as a good descriptive instrument for functional ability. It was used in most of the work disability studies cited in the literature review, leading to its use in this study to enable comparisons with prior research. Higher scores indicate greater disability in activities of daily living.

The arthritis *Self Efficacy Scales* (Lorig, Chastain, Ung, Shoor, & Holman, 1989) were designed "to measure patients' perceived self efficacy to cope with the consequences of chronic arthritis" (p.37). Self efficacy refers to a person's belief or confidence that he or she can perform a specific behaviour or task in the future. There are three subscales: pain (5 items), function (9 items) and symptom management (6 items). Respondents indicate how certain they are that they can perform the specified behaviour on a scale of 10 (very uncertain) to 100 (very certain). The mean is calculated for each subscale. Test-retest reliabilities for individual items ranged from .71 to .85 (Pearson's r) in a sample of 91 arthritis subjects (Lorig et al., 1989). The subscale retest reliability coefficients were .87 for pain, .85 for function, and .90 for other symptoms in the same sample. It has been used in conjunction with the Arthritis Self Management Program in Canada, the United States, and other countries, to measure perceived self efficacy in patients with a range of rheumatological conditions. Higher scores indicate greater self-efficacy.

The SF-36 Health Survey is a generic measure of health status widely used in both population and clinical studies (McDowell & Newell, 1996; Ware, Snow, Kosinski, &

Gandek, 1993) and utility of the SF-36 and the briefer SF-12 have been assessed in patients with RA (Hurst, Ruta, & Kind, 1998). It consists of 36 items measuring 8 dimensions: physical functioning, role limitations due to physical health, bodily pain, social functioning, mental health, role limitations due to emotional health, vitality (or fatigue), and general health perceptions. Numerous studies have been conducted assessing its psychometric properties. The median alpha coefficients for internal consistency exceed 0.80 for all subscales except social functioning (0.77), and test-retest correlation coefficients range from 0.60 to 0.90 (McDowell & Newell, 1996; Ware et al., 1993). Construct validity has been demonstrated in a variety of studies, and the scales discriminate between types and levels of diseases and health states. In a study of 223 British patients with RA, the 2-week test-retest reliability ranged from ICCs of 0.76 to 0.93, depending on the subscale (Ruta, Hurst, Kind, Hunter, & Stubbings, 1998). Additionally, there was a consistent and predictable relationship between the SF-36 scores and a number of disease-specific measures of impairment and disability, supporting its construct validity. However, it did not discriminate between functional categories of patients at the more disabled end of the continuum (Ruta et al., 1998). Modified HAQ scores are significantly correlated with SF-36 physical component scores (-0.77) and have been shown to predict 60% of the variance in the physical component scores of the SF-36 in a sample of 233 adults with RA (Hurst et al., 1998). In the present study, the SF-36 was administered in its entirety. However, it was recognized that the HAQ and SF-36 physical function subscale scores were measuring the same construct and were likely to be highly correlated, and this was taken into account in the analysis plan.

A special note about the interpretation of SF-36 scores: a higher score indicates better health status for each item. While this is intuitive for most of the items (e.g., a higher physical function score indicates better physical function status), it is counter-intuitive for the bodily pain scale. A higher score in bodily pain indicates *less* pain (the desirable end of the health status continuum), not more pain.

The *Multidimensional Scale of Perceived Social Support* (MSPSS) (Zimet et al., 1988) is a 12-item, self-report measure of perceived social support from significant other, family and friends. Social support scales in general may measure the number of people in a

support network, the quality of the support, the perceived adequacy of the network, or other features of social support. The MSPSS measures perceived adequacy by asking respondents to rate the support received on a 7-point Likert scale. Mean scores are calculated for 3 subscales and the total scale. Although developed using younger adults, it was selected for the present study because it was brief, addressed support from family, friends and significant others (which were mentioned by participants as important factors during the survey development phase of the present study), and had adequate reliability. Cronbach's coefficient alpha, in a sample of 275 subjects, was 0.91 for the significant other subscale, 0.87 for family, 0.85 for friends, and 0.88 for the total scale. In retests of 69 subjects, the reliability coefficients were .72, .85, .75, and .85, respectively. Principal components factor analysis supported the three subscales, with the expected four items loading on each of the three factors (significant other, family, friends). Similar psychometric properties were reported in a subsequent study, by different investigators, of Canadian young adults with and without psychiatric diagnoses (Kazarian & McCabe, 1991). They also reported satisfactory construct and discriminant validity (Kazarian & McCabe, 1991). The three subscales were used in the present study in order to capture different sources of social support. Higher scores indicate higher levels of social support.

The *Job Content Questionnaire* (JCQ) (Karasek et al., 1998) is an instrument designed to measure the "content" of the respondents' work tasks in a way that is broadly applicable to all jobs and all job holders. It has been used in studies of job strain associated with cardiovascular disease, musculoskeletal injuries, psychological distress and chronic illness in the United States and internationally. The JCQ addresses the psychological and social structure of the work, such as work demands, decision-making, and social interaction. Its internal consistency, test-retest reliability, discriminant and criterion validity have been established in several studies, including computer company employees in Japan, telecommunications workers in Canada, blue collar workers in Quebec, and the longitudinal Nurses Health Study in the United States (Achat, Kawachi, Byrne, Hankinson, & Colditz, 2000; Brisson et al., 1996; Karasek et al., 1998; Kawakami & Fujigaki, 1996; Schechter, Green, Olsen, Kruse, & Cargo, 1997). In these studies, internal consistency for the subscales ranged from .69 to .83 (coefficient alpha). Achat and colleagues (2000) reported test-retest

reliabilities exceeding .90. Validation studies indicated strong associations between jobs with high demand and low control (measured by JCQ subscales) and high levels of stress, greater absenteeism, and poorer self-concept of health (Schechter et al., 1997). The dimensions of skill discretion, decision authority, psychological demand, supervisory support and co-worker support have been confirmed through various factor analyses (Karasek et al., 1998).

The JCQ was developed to be broadly applicable to all types of jobs, and a review of content indicted that it contained items identified as potential issues during the RA client group discussions. The subscales used in the present study were skill discretion, decision authority, psychological demand, co-worker and supervisory support, and physical job demands. The JCQ was used in one prior study of people with arthritis, recently completed and only available in abstract form (Lacaille et al., 1999). The co-worker support subscale refers to "the people I work with" so was applicable to unpaid as well as paid workers in the present study. Supervisory support applied only to paid workers with a supervisor. These two items were considered indicators of the social environment, all other JCQ subscales were occupation characteristics. Higher scores indicate strong agreement that the characteristic is present (e.g., high skill discretion scores indicate that the work permits a high level of discretion, high physical demand scores indicate that the work is physically demanding).

Variable	Definition	Possible Score Range
paid work	self-reported hours of paid work last week	0 to 168 ¹
unpaid work	self-reported hours of all unpaid work last week: household work, home maintenance, care-giving, volunteering, studying	0 to 168 ¹
total work	sum of paid and unpaid work hours last week	0 to 168 ¹
work limitation	self-reported limitation in ability to work due to arthritis	work limited (0)
		work not limited $(1)^2$
work satisfaction	self-reported rating of satisfaction with performance of main work activity	1 (very dissatisfied) to
		10 (very satisfied)

Table 5. Outcome (Dependent) Variables in Cross-sectional Survey

¹ This is a theoretical range: 24 hrs per day x 7 days = 168. Actual upper limit was expected to be lower.
 ² Where appropriate, "work not limited" could be further classified into "I work more hours than I want to" and "I work as much as I want to."

Variable	Definition and Source Instrument	Possible Score Kange
I. Person Characteris	tics:	
age	age in years	18 to 66
gender		male = 0, female = 1
education	highest level of formal education attained	< post-secondary graduation = 0
	•	post-secondary graduate $= 1$
disease duration	years since diagnosis of RA	1 to 50
functional status	ability to perform 8 activities of daily living	0.00 (able) to 3.00 (disabled)
	(HAQ)	
self efficacy	belief that one can control one's pain	10 to 100
pain	(Lorig's SES)	(very uncertain to very certain)
self efficacy	belief that one can perform basic activities	10 to 100
function	(Lorig's SES)	(very uncertain to very certain)
self efficacy	belief that one can control other symptoms	10 to 100
symptoms	(Lorig's SES)	(very uncertain to very certain)
health status,	overall health	5 to 25
general health	(SF-36)	(poor health to excellent health)
health status,	ability to do physical activities	10 to 30
physical function	(SF-36)	(high score = better function)
health status,	extent to which physical health impacts	4 to 8
role: physical	activities (SF-36)	(high score = better function)
health status,	extent to which emotional health impacts	3 to 6
role: emotional	activities (SF-36)	(high score = better function)
health status,	ability to engage in social activities	2 to 10
social function	(SF-36)	(high score = better function)
health status,	absence of pain	2 to 12
bodily pain	(SF-36)	(high score = less pain)
health status,	amount of energy (or lack of fatigue)	4 to 24
vitality	(SF-36)	(high score = more energy)
health status	experience of mental (ill) health symptoms	5 to 30
mental health	(SF-36)	(high score = better function)
occupational balance	satisfaction with one's balance of time spent	1 to 10
-	on work, self-care, leisure and rest	(very dissatisfied to very satisfied)
		- /

Table 6. Potential Explanatory (Independent) Variables

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II. Environment Characteristics:				
co-worker support	perceived support from "people I work with" (JCQ)	6 to 24		
supervisory support	perceived support from work supervisor (JCQ) (applies only to respondents with a supervisor)	5 to 20 (less support to more support)		
commuting difficulty	perceived difficulty with commute to work (applies only those who commute)	1 to 10 (very difficult to not at all difficult)		
social support	perceived support from significant other, family, friends (3 MSPSS subscales)	1 to 7 (less support to more support)		
marital status		single, separated/divorced, widow=0 married, living with partner = 1		
household size	number of people in household this variable has two subsets: (a) number of adults and (b) number children under 18	1 to 6		

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.../continued

Variable	Definition and Source Instrument	Possible Score Range
III. Occupation Cha	racteristics:	· · · ·
job type	response to "what do you consider to be your main occupation?" National Occupational Classification was used to code stated occupation; NOC codes were subsequently reduced to 6 categories	managerial professional services trades household workers retired
skill discretion	flexibility the worker has in deciding which skills to use (JCQ)	12 to 48 (less to more skill discretion)
decision authority	autonomy to make decisions about work (JCQ)	12 to 48 (less to more autonomy)
psychological demand	psychological demands of work tasks (JCQ)	18 to 72 (less to more demand)
physical demand, isometric	isometric demands of work tasks, i.e., static work postures (JCQ)	2 to 8 (low to high demand)
physical demand, exertion	physical exertion demanded by work tasks (JCQ)	3 to 12 (low to high demand)

Table 6. Potential Explanatory (Independent) Variables, continued.

IV. Additional Descriptive Characteristics:

main work category	self-reported category of work which best reflects respondent's main occupation	household full-time employment part-time employment self-employed student volunteer
		retired
household income	approximate household income from all	<\$10,000
	sources last year	in \$10,000 increments to
		> \$70,000
disability benefits	receipt of disability pension	yes (1), no (0)
global disease activity	respondent's overall impression of how active	0 to 10
	RA was when survey was completed	(not active/in remission to very
	(10 cm visual analog scale/VAS)	active/bad flare)
global pain	respondent's overall rating of pain from RA	0 to 10
	when survey was completed (10 cm VAS)	(no paid to pain as bad as can be)
global fatigue	respondent's overall rating of fatigue from RA	0 to 10
	when survey was completed (10 cm VAS)	(none to most severe fatigue ever)
3.4 Data Management

Data from surveys were entered into a desktop statistical package (SPSS version 9.0) by a research assistant. Spreadsheets were visually scanned for empty cells, missing values and errors by conducting random spot checks for accuracy of data entry. This verification process occurred twice, once by the research assistant and once by the investigator. Frequency tables, histograms, bar charts, and descriptive statistics were used to scan the data for out of range or odd values.

Empty cells and missing data were double-checked by referring back to the original survey. Missing items were coded as appropriately missing (some questions were not appropriate for all respondents, for example, supervisory support questions), or inappropriately missing (items for which there should have been a response, but were left blank by the respondent). Missing values for items within pre-existing scales were handled in accordance with the procedures for that scale. If a scale did not have published directions for handling missing data, the approach from the SF-36 Health Survey was used. The SF-36 procedure states that "a scale score be calculated if a respondent answered at least half of the items in a multi-item scale (or half plus one in the case of scales with an odd number of items.)...A psychometrically sound estimate is the average score, across completed items in the same scale, for that respondent....For example, if a respondent leaves one item blank in the 5-item Mental Health scale, substitute the respondent's average score (across the four completed mental health items) for that one item" (Ware et al., p. 6:17). This same procedure has been used for missing data in the JCQ (Koehoorn, 1999).

In isolated cases, the missing item for demographic characteristics could be inferred from other responses within the individual's survey. For example, missing gender could be inferred as female from the respondent's written comments about being a wife and mother. Missing values for other demographic data, e.g., household income, which could not be reasonably presumed from other comments, were left missing.

Responses were transformed into numerical scale scores for the HAQ, the Self Efficacy Scales, the SF-36 Health Survey subscales, the Multidimensional Scale of Perceived Social Support, and the Karasek Job Content Questionnaire subscales, in accordance with the algorithms provided by the individual test authors. Twenty randomly selected cases were scored by hand to verify that the correct formulae were entered into the computer.

3.5 Data Analysis

Descriptive statistics were produced for each variable in the survey. Hours of paid and unpaid work were compared to hours worked by the general population in Canada. Differences between sub-groups (e.g., differences in work hours for men and women) were assessed using t-tests (for continuous data) and Chi square tests (for categorical data). Levene's test for equality of variance was used with the t-tests, and the appropriate level of significance for comparing means was reported. Analysis of variance was used to compare participants' work hours when there were three groups (e.g., three levels of work limitation). Spearman correlation coefficients were used to assess the relationships between paid, unpaid, and total work and disease status variables (because disease status was skewed toward less severe disease). The association between each potential explanatory variable and the outcome variables of unpaid, paid, and total work hours was assessed using univariate regression, controlling for age and gender. Univariate regression coefficients were also calculated for each explanatory variable with the secondary outcome measure of work satisfaction as the dependent variable. Alpha of .05 was used to infer statistically significant differences or associations in the preceding analyses.

Since the main thrust of the study was to predict paid and unpaid work hours, and secondarily to predict work satisfaction and work limitation due to arthritis, this guided the analysis plan. Up to 30 candidate variables could be considered in predictive models. Data reduction techniques such as factor analysis and principal component analysis were considered inappropriate for the set of explanatory variables in the study because the variables measure several different constructs. Both factor analysis and principal component analysis are intended to reduce the number of variables within a set of measures of the same construct (Kleinbaum et al., 1998). Further, data reduction techniques make it difficult to

interpret results. Although they may lead to an improved statistical model, it may be difficult to describe the model in a meaningful way. For example, suppose principal component analysis was used to reduce the number of candidate variables. Say that one resulting component related to "physical capacity" and was comprised of several measures, and further, that this factor was found to be a significant predictor of paid and unpaid work. We would be able to infer that physical capacity was related to participation in work, but it would be difficult to state what kind of a change in physical capacity would result in a one-unit change in work hours. But, if the relative contribution of each potential explanatory factor was assessed in turn, leaving the measures intact (the way they are used in clinical and community settings), then it would be possible to convey the study results in terms that would be meaningful to people with RA and the health providers working with them. For example, a 5% increase in HAQ score might correspond with a 1-hour reduction in work hours per week.

Linear regression models were constructed with hours worked (paid or unpaid), and work satisfaction as dependent variables. The person, environment, and occupation variables listed in Table 6 were considered potential independent (or predictor) variables. Similarly, a logistic regression model was built with work limitation (work limited due to arthritis versus no limitations) as the dependent variable. Model building proceeded as follows:

First, scatterplots were created for each potential explanatory variable plotted against paid work hours, unpaid work hours, and work satisfaction to determine that a linear model would be appropriate. Inter-correlations among potential explanatory variables were assessed using Pearson's correlation coefficients. Because it was anticipated there would be several inter-correlations, a hierarchical approach (Norman & Streiner, 1994) was employed using a set of 8 variables as an initial model, followed by systematically assessing the contribution of each remaining independent variable in turn. In this way, the intercorrelations did not mask the effect of any one variable, because variables were evaluated one at a time. The variables in the initial model were chosen based on the results of prior work disability studies, to see if they would also predict hours of paid and unpaid work. They were age, gender, pain, functional status (HAQ score), skill discretion, decision

authority, physical demand (exertion), and co-worker support. For predicting unpaid work, family social support replaced co-worker support.

For linear regression analyses, the *a priori* variables were entered into a model in a single block, to assess their overall effect as a group. Then, a forward stepwise procedure was used, with F-to-enter set at .10, in order to retain all variables close to the conventional level of significance ($p \le .05$) throughout the steps. Each remaining candidate variable was added in turn, to see if it would improve the model comprised of the significant predictors from the initial set. Variables that made a significant contribution, adding more than 2% to R^2 , were identified. Additional variables identified in this process were entered in a single block to the variables remaining from the initial model, again using a forward stepwise procedure. Significant predictors remaining at the end of this process comprised the final model. If the additional set of variables included highly correlated variables ($\ge .5$) that measured the same construct, only one was selected for entry into the final regression. For example, the HAQ and the SF-36 Physical Function subscale both assessed functional status. In this case, the HAQ was selected to represent functional status.

For the secondary outcome measure of satisfaction with work performance, all candidate variables were entered into an exploratory analysis, using forward stepwise procedures with F-to-enter set at .10. For the secondary outcome measure of work limitation, a binary outcome, logistic regression was used. First, the 8 *a priori* variables were entered into a model. Those with significant odds ratios were retained. Each remaining candidate variable was added to this model in turn, in the same systematic process as for the multivariable linear regression outlined above. Those with significant odds ratios were identified and entered into a final model. Odds ratios and 95% confidence intervals were calculated for all predictors in the final model.

Residual analyses were conducted to check that model assumptions had not been violated, and to identify potential influential cases. Predicted values were plotted against standardized residuals. Regression analyses were repeated using the final predictive models with the influential cases removed.

The results of the main multivariable analyses suggested some additional analyses. Multiple linear regression analysis using the same factors in the final model for paid work was repeated with a sample restricted to women only. The unpaid work analysis was repeated with two sub-groups, participants with and without children. Logistic regression, with work limitation as the dependent variable, was repeated for two sub-groups (paid and unpaid workers), for comparison with the results from the sample as a whole.

Chapter IV Results

4.1 Respondent Characteristics

The final sample was comprised of 239 adults with RA. Detailed response rate information is illustrated in Figure 4 and Table 7. Overall, 40% of those receiving an invitation completed surveys, and the proportion agreeing to participate from each physician's office was approximately equal. Of those initially agreeing to participate, the response rate was 89%. There were 194 women (81%). The mean age was 50.3 years (SD = 10.3), and the median age was 52. On average, they reported having RA for 12.7 years (SD = 9.6), with median disease duration of 11 years. Approximately 75% stated they were taking at least one anti-rheumatic drug, 15% were taking non-steroidal anti-inflammatory drugs alone, 5% were not taking any medications, and 5% did not specify their medications.

Thirty-six participants (15%) stated they received a disability pension. The median annual household income category was \$40,001-50,000. This is similar to the 1999 median family income in Canada (\$47,300), and slightly lower than the median family income for the city of Vancouver (\$52,600) (Statistics Canada, 2000). Because all the referring rheumatologists practiced in the Lower Mainland, the majority of participants resided in the Lower Mainland and Fraser Valley, although several came from other health regions in British Columbia (see Table 8). They represented a range of functional limitations associated with RA, with HAQ disability scores ranging from 0 (no limitations in activities of daily living) to 2.38 (great difficulty with ADL). The mean HAQ disability score was 0.46 (SD = 0.42), with a median of 0.38, suggesting the sample was skewed toward the less disabled end of the continuum.

Respondents returned the surveys between October 1999 and May 2000.



Figure 4. Response Rate Flow Chart.

Physician	Invitations sent ¹	Invalid address ²	Surveys sent ³	Response rate 1 ⁴	Refused consent ⁵	Surveys received	Response Rate 2 ⁶	Response Rate 3 ⁷
Α	50	1	23	23/49 46.9%	1	19	19/23 82.6%	19/49 38.7%
В	133	10	.50	50/123 40.6%	1	43	43/50 86.0%	43/123 35.0%
С	225	17	98	98/208 47.1%	0	81	81/98 82.7%	81/208 38.9%
D	134	9 + 1 deceased	55	55/124 44.4%	0	51	51/55 92.7%	51/124 41.1%
E&F	110	11	43	43/99 43.4%	0	40	40/43 93.0%	40/99 40.4%
Physician Unknown ⁸	n/a	n/a	n/a	n/a	n/a	6	n/a	n/a
TOTAL	652	49	269	269/603	2	240	240/269	240/603

Table 7. Response Rates Traced by Referring Physician.

Notes:

- 1. invitations sent = the total number of addressed envelopes that went into the mail
- 2. invalid address = the number of invitations that came back 'return to sender'
- 3. surveys sent = the number of invited patients who released their name and address to the investigator (registered for the study) and were sent a survey

45%

- 4. response rate 1 = [#surveys sent / (#invitations sent #invalid addresses)] x 100, an estimate of the proportion of invited patients who registered for the study
- 5. refused consent = the number of surveys returned blank with a note that declined participation in the study
- response rate 2 = [#surveys received / #surveys sent] x 100, the return rate for surveys sent to registrants. The row labeled TOTAL includes 6 surveys that cannot be attributed to a specific physician (see note 8).
- response rate 3 = [#surveys received / #invitations sent #invalid addresses] x 100, the return rate for those presumed to have received an invitation to participate. The row labeled TOTAL includes 6 surveys that cannot be attributed to a specific physician (see note 8).
- 8. 6 surveys were returned with identification codes missing (either the research assistant forgot to code the envelope, or the respondent did not use the envelope provided). n/a = not applicable.

89%

40%

Region	Respondents	Region	Respondents
Vancouver/Richmond	41	Central Vancouver Island	1
Simon Fraser	72	South Okanagan	1
South Fraser Valley	79	Cariboo	2
Fraser Valley	25	East Kootenay	2
North Shore	. 9	Northern Interior	2
Coast Garibaldi	3	Northwest	1
Capital Health	1	non-BC (Yukon)	1

Table 8. Distribution of Respondents Across Health Regions in British Columbia.

4.2 Missing Data

Very few items were omitted in the surveys. Respondents with missing data completed at least half of each scale, therefore, missing data were handled as described in Chapter 3. The most frequently omitted item was household income, which was left blank by 20 respondents. Because this could not be inferred, it was left as missing. Isolated items in the JCQ were omitted by 9 respondents. Appropriately, only those who stated they had a work supervisor answered the JCQ items about supervisory support (n = 101). Isolated items in the SF-36 were omitted by 7 respondents. Six respondents omitted the item on educational level, and five omitted the item on household size. These were left as missing. Three omitted the item on gender, but this was reasonably inferred as "female" from written comments about being a mother in all three cases. The item on commuting difficulty was only applicable to the 125 respondents who regularly commuted to a paid work setting. The occupation characteristics from the JCQ were specifically related to the main work category cited by the respondent. Therefore, only responses from those who were rating unpaid work tasks could be used to predict unpaid hours, and only those rating paid work tasks could be used to predict paid work hours. Thirty respondents completed the JCQ items for both their paid and unpaid work, giving samples of 110 and 143, respectively, for the JCQ items. Other than the exceptions noted in this paragraph, results are based on responses from all 239 participants.

4.3 Participation in Paid and Unpaid Work: Hours Worked

How much do adults with RA work? More than half of the respondents (n = 136) engaged in paid work (median = 15 hrs), and all but one (n = 238) engaged in unpaid work (median = 29 hrs) in the week prior to completing the survey. Overall, the sample reported an average of 47 hours of work, just under 19 hours of unpaid work and 28 hours paid work. In terms of their main form of work, 84 identified themselves as household workers, 126 were paid workers (76 full-time, 30 part-time, and 20 self-employed), 3 were students, 6 were volunteers, 16 labeled themselves as retired and 2 stated "other."

One "other" respondent was looking for work, and since she reported household work hours but no paid work hours, she was moved into the household work category. The second "other" respondent specified "managing my RA" as her work category. Again, she reported household work hours but no paid hours, so was moved to the household work category. Since there were so few students and volunteers, their surveys were examined to see if they could be combined with the household or paid worker groups. One student worked half-time, and responded to work-related questions using the part-time job, so was moved to the parttime employee category. The remaining students and volunteers reported household work in addition to volunteer hours and studying, so were combined with the household workers, and the category was re-labeled unpaid workers.

As illustrated in Figure 5, participants classified their main form of work by the relative hours spent doing paid or unpaid types of work. The 16 retired participants were excluded from the figure. Table 9 more fully describes the hours worked by each group of workers.



Figure 5. Average Hours Worked Last Week for Sub-groups of Respondents. Grouped by main work category: unpaid, full-time employee, part-time employee, self-employed. Excludes retired respondents, thus n = 223. Type of work hours: hh = household work, hm = home maintenance, cg = caregiving, vol = volunteer work, st = studying, pd = paid work.

		Hours Wo	orked Las	t Week: N	Aeans and	(Standard	Deviation	is)	
	n	house- hold	home maint	care giving	volun- teer	study	paid work	all unpd ¹	total work ²
Unpaid Workers	96	24.3 (16.1)	2.7 (4.0)	10.2 (18.1)	1.4 (2.7)	1.3 (5.4)	4.3 (10)	40.1 (29.8)	44.4 (32.7)
Full-Time Employees	76	11.9 (8.2)	3.0 (3.8)	2.5 (9.1)	0.51 (1.2)	0.83 (3.9)	36.3 (14.7)	18.7 (15.2)	55.0 (20.8)
Part-Time Employees	31	16.6 (20.1)	1.4 (2.5)	4.8 (11.8)	1.1 (2.8)	1.4 (6.3)	21.0 (10.7)	25.4 (23.9)	46.4 (29.6)
Self-Employed	20	10.8 (7.4)	2.7 (3.1)	2.7 (5.9)	1.7 (2.1)	0.8 (2.3)	30.5 (21.6)	18.6 (11.3)	49.1 (29.7)
Retired	16	11.47 (9.75)	3.25 (4.68)	1.06 (2.26)	1.38 (3.14)	0.25 (1.00)	0.00	17.41 (15.03)	18.37 (15.04)

Table 9.	Average	Hours	of Paid	and Ur	paid '	Work	Classified	by	Main	Work	Category.

 $\frac{1}{2}$ "All unpd" is the sum of household, home maintenance, caregiving, volunteering, and studying.

² "Total work" is the sum of paid work and all unpaid work.

Several participants worked a large number of hours overall. All cases reporting \geq 70 hours per week are identified in Appendix 11. For these participants, responses to the paid and unpaid work questions were verified by reviewing each person's Occupational Questionnaire. With the exception of one respondent who reported caregiving for 168 hours (or 24 hours per day), all values \geq 70 hours were reasonably supported by the pattern of work documented in the OQ diary. The one extreme value of 168 was truncated to 70 hours. This was based on the similarity of OQ records for caregiving and other types of work reported by this individual and another participant, who reported 70 hours of caregiving.

Does work participation differ by gender, age, disease status or functional status? There were gender differences in all forms of unpaid work studied, except for student work (see Table 10). Women performed more hours of household work (p < .001), caregiving (p = .003), and volunteer work (p = .01), and less home maintenance (p = .02) than did men. Although men worked more paid hours than women, when adjusted for unequal variances in the two groups, this difference was significant only at the p = .06 level. The difference in total work hours between men and women was not significant.

To help describe the effects of age and disease status, the sample was split into two groups using the median age and median visual analog score for disease activity, pain and fatigue. The sample was split into three groups for functional status, indicating those with no limitations in activities of daily living (HAQ = 0), those with mild limitations (HAQ > 0 < 1) and those with moderate to severe limitations (HAQ \geq 1). Mean work hours and standard deviations for all the preceding sub-groups are reported in Table 10. The relationships between each of these four disease/functional status indicators, age, and the outcomes of paid, unpaid, and total work hours were evaluated statistically using Spearman correlation coefficients (Table 11).

Household work hours were significantly and inversely associated with pain and fatigue. Home maintenance hours were similarly associated with age, disease activity and pain. The only significant association with care-giving hours was an inverse relationship

with age, and studying was inversely associated with both age and pain. There were no significant associations with volunteer work hours. Overall, more unpaid work hours were significantly associated only with reports of less pain. More paid work hours were significantly associated with younger age and better functional status. A cumulative effect was suggested with total work hours being significantly and inversely associated with age, disease activity, pain and functional status. None of the correlation coefficients were large in magnitude, the strongest correlation was between age and total work hours at -.37.

Hours Worked Last Week: Means and (Standard Deviations)									
Grouping	n	house-	home	care	volun-	study	paid	all	total
variable	7.00	hold	maint	giving	teer		work	unpaid	work
All subjects	220	17 28	2.67	5 9 1	1 1 2	1.07	19 56	28.04	16 60
All subjects	239	(14.88)	(3.75)	(13.84)	(2.35)	(4.67)	(10.30)	(25.04)	(28.97)
		(14.00)	(5.75)	(15.04)	(2.55)	(4.07)	(1).77)	(25.01)	(20.77)
Gender									
male	45	9.36	3.84	2.47	0.47	1.53	24.23	17.67	41.9
		(9.37)	(3.51)	(5.41)	(1.49)	(5.53)	(23.00)	(13.83)	(29.20)
female	194	19 36	2 39	6 59	1 27	0.96	17 24	30.45	47 69
Temate	174	(15.32)	(3.76)	(15.05)	(2.48)	(4.45)	(18.34)	(26.40)	(28.89)
		()	()	()	()	()	(1000 1)	(20110)	(2010))
p (t-test)		<.001	.02	.003	.01	.46	.06	<.001	.23
	110	17.40	0.05	0.05	1 10	1 42	95.01	<u> </u>	56.54
< 52 years	118	17.40	2.25	9.25	1.19	1.43	25.01	31.52	56.54
		(10.12)	(2.97)	(17.70)	(2.31)	(3.41)	(19.12)	(28.00)	(29.98)
> 52 years	121	17.36	3.07	2.45	1.05	0.72	12.26	24.65	36.91
		(13.64)	(4.36)	(7.02)	(2.38)	(3.79)	(17.67)	(20.49)	(24.42)
Disease Activity ¹		. ,	, ,		<u> </u>		· · · · · · · · · · · · · · · · · · ·		<u>``</u>
\leq 4.8 cm	123	18.69	2.98	6.64	1.04	0.88	20.04	30.23	50.27
less active		(13.93)	(3.97)	(15.06)	(2.33)	(2.90)	(19.61)	(25.65)	(27.40)
> 1.8 cm	116	15 00	2 22	1 01	1 20	1 27	16 00	25 72	42 70
more active	110	(15.78)	(3.50)	(12.41)	(2.37)	(6.01)	(19.23)	(24.21)	(30.18)
Perceived Pain ¹		()	(1.1.1)	()	()	(0.01)	(17.22)	(== 1)	(20112)
\leq 4.2 cm	120	18.87	2.82	6.43	1.21	1.06	19.55	30.39	49.94
less pain		(14.52)	(3.84)	(14.36)	(2.76)	(3.40)	(20.08)	(26.05)	(27.97)
	110	15.00	0.50	5 1 0	1.02	1.00	19.55	a 5 6 6	42.22
> 4.2 cm	119	15.88	2.50	5.18	1.03	1.08	1/.55	(23.68)	(20.60)
Perceived Fatigue	i	(15.10)	(3.07)	(15.55)	(1.65)	(3.09)	(10.01)	(23.79)	(29.09)
< 5.0 cm	122	19.72	2.82	5.23	1.11	0.81	7.05	29.51	46.73
less fatigue		(13.95)	(3.76)	(12.23)	(2.54)	(3.14)	(18.89)	(26.04)	(25.98)
Ũ		、 <i>、</i>	~ /	```	. ,	· · ·	()	· · ·	· · ·
> 5.0 cm	117	14.94	2.50	6.42	1.13	1.34	20.13	26.33	46.46
more fatigue		(15.48)	(3.76)	(15.38)	(2.13)	(5.85)	(19.97)	(25.70)	(31.91)
Functional Status		10.00	2.20		0.01	1.07		22.20	<i></i>
HAQ = 0	58	19.69	3.29	8.03	(2.25)	1.37	22.14	33.28	55.42
more able		(19.05)	(4.3)	(10.48)	(2.33)	(3.36)	(19.61)	(29.51)	(31.23)
HAQ > 0 < 1.0	152	16.88	2.38	5.34	1.1	0.86	18.76	26.56	45.32
		(13.32)	(3.4)	(13.0)	(2.28)	(3.82)	(19.77)	(23.2)	(28.05)
		```		```	、 ,	. ,	```	``'	` '
$HAQ \ge 1.0$	29	15.41	2.88	3.84	1.62	1.59	10.33	25.34	35.67
less able		(13.06)	(4.29)	(12.23)	(2.68)	(6.54)	(15.02)	(23.77)	(24.79)

#### Table 10. Average Hours of Paid and Unpaid Work by Adults with RA.

¹ split into two groups at the median score for the study sample.
 ² HAQ scores of 0 indicate no reported limitations in activities of daily living; <1 indicate mild impairment; ≥ 1 indicate moderate to severe impairment.

Characteristic	house- hold	home maint	care giving	volun- teer	study	paid work	all unpaid	total work
Age (yrs)	.03	.02	23**	10	16*	35**	11	37**
Disease Activity (0-10)	11	15*	06	.02	09	09	13	17*
Perceived Pain (0-10)	14*	15*	06	.08	13*	06	14*	15*
Perceived Fatigue (0-10)	21*	09	.05	.03	.04	.04	10	03
Functional Status (HAQ)	07	07	08	.12	02	15*	09	19**

 Table 11. Associations Between Hours of Paid and Unpaid Work and
 Selected Characteristics of Study Sample (Spearman's rho, n=239)

* *p*≤.05

** *p*≤.01

How do work hours in this sample of adults with RA compare with the general population in Canada? Results from the Statistics Canada General Social Survey of 1998 provide some figures for comparison (Statistics Canada, 1999). The GSS data were collected from a sample of 10,749 people interviewed by telephone. The target population included all people aged 15 and over, except full-time residents of institutions, in the 10 provinces. Data were collected each month from February 1998 to January 1999, using random digit dialing and distributing the sample evenly over the 12 months. The response rate was 77.6%. The hours documented in this preliminary report were mean hours per day averaged over a 7-day week, and were presented for the full sample as well as by age and gender sub-groups. To make comparisons with the present RA study sample, the GSS results from the 35-44, 45-54, and 55-64 year old age groups were used. (Only 16 of the RA sample were adults under 35, all women.) The GSS hours per day were multiplied by 7 so that the unit of comparison was hours per week for each group. The GSS collected time use data for several categories of activity beyond those included in the present RA study. The GSS categories of total work, paid work, home maintenance, childcare, civic and voluntary activity and educational activity matched the definitions of total work, paid work, home maintenance, care-giving, volunteering and studying used in the RA study. The GSS category of all household work minus the hours spent in childcare and home maintenance corresponds to household work hours in the RA group. Hours are compared in Table 12.

No statistical comparison was made because only limited GSS summary data were available, and because the GSS is a representative sample of the general population with more even distribution across age and gender than the RA sample is of adults with RA. However, comparison figures in Table 12 suggest that people with RA worked fewer hours than did the population in Canada (total work). Both men and women with RA reported fewer hours of household work and paid work than adults in the general population survey, although the difference in paid work hours for women was small (less than 3 hours). In the categories of caregiving and studying, the RA respondents reported more hours than the general population respondents. And among men, the RA respondents reported more hours spent in home maintenance.

	ma	iles	fem	ales
Type of work	RA sample (n = 45)	General population ¹	<b>RA sample</b> (n = 174)	General population ¹
household work	9.4	15.2	19.6	24.7
home maintenance	3.8	2.1	2.7	3.3
care-giving	2.5	1.9	6.7	3.0
volunteering	0.5	2.8	1.2	3.5
studying	1.5	0.2	0.8	0.7
paid work	24.2	32.2	17.1	19.8
Total Work	41.9	54.6	47.9	55.3

Table 12. Hours of Work per Week by Adults with RA (aged 35-66) Compared to theGeneral Population in Canada (aged 35-64).

¹ General population data from: Statistics Canada. (1999). Overview of the Time Use of Canadians in 1998.

#### 4.4 Work Satisfaction and Work Limitation

The two secondary outcome measures were work satisfaction and work limitation. *Are people satisfied with their ability to perform their main form of work?* The average work satisfaction rating for the sample was 6.8 (SD = 2.4). The distribution is illustrated in Figure 6. More than half the respondents (n = 148) reported high levels of satisfaction (7 and higher). Unpaid workers, with a mean rating of 6.3, were slightly less satisfied than paid workers, with a mean of 7.2 (p = .01).



Figure 6. Distribution of Ratings for Satisfaction with Performance of Main Work Activity. n = 239.

Do people who report working less than they want to because of their arthritis have different work patterns than those who do not report limitations? Respondents were initially placed in one of three categories: those limited by their arthritis (n = 72), those working as much as they wanted to (n = 112), and those working more than they wanted to (n = 55) (see Table 13). Comparing hours of work across these three categories using analysis of variance showed that paid work and total work hours differed significantly. People limited by their arthritis worked fewer hours than both of the 'not limited' groups. When the categories were reduced to two, limited versus not limited (see Table 14), the results were similar, with those who were limited by their arthritis working an average of 6 paid hours per week compared to 24 hours by those not reporting limitations (p < .001). There were no significant differences in hours worked for any of the unpaid work categories.

Multiple and the second	Mean hours worked "last week" (standard deviation)										
	n	house- hold	home maint	care giving	volun work	study	paid work*	all unpd work	total work*		
Limited "I don't work as much as I want to b/c of my arthritis"	72	17.28 (14.17)	2.65 (4.09)	5.75 (13.97)	1.33 (2.37)	0.95 (4.31)	6.33 (11.50)	27.96 (23.20)	34.30 (25.95)		
Not Limited "I work as much as I want to"	112	18.99 (16.84)	2.68 (3.67)	5.65 (14.35)	1.03 (2.28)	1.16 (5.45)	18.93 (18.81)	29.52 (27.88)	48.45 (30.27)		
Not Limited "I work more than I want to"	55	14.23 (10.69)	2.64 (3.53)	6.21 (12.82)	1.03 (2.48)	1.04 (3.26)	33.80 (18.12)	25.14 (20.94)	58.94 (23.79)		

#### Table 13. Average Hours of Work for Participants Reporting Work Limitation Compared with Two Sub-groups without Work Limitations.

*  $p \le 0.001$ , ANOVA comparing all three groups.

#### Table14. Average Hours of Work for Participants Limited by Arthritis Compared with Participants Not Limited by Arthritis.

	Mean hours worked "last week" (standard deviation)											
	n	house- hold	home maint	care giving	volun work	study	paid work*	all unpd work	total work*			
Limited	72	17.28 (14.17)	2.65 (4.09)	5.75 (13.97)	1.33 (2.37)	0.95 (4.31)	6.33 (11.50)	27.96 (23.20)	34.30 (25.95)			
Not Limited ¹	167	17.42 (15.23)	2.67 (3.61)	5.84 (13.83)	1.03 (2.34)	1.12 (4.83)	23.83 (19.82)	28.08 (25.82)	51.91 (28.66)			

*  $p \le 0.001$ , t-test comparing "limited" to "not limited." ¹ The two "not limited" categories have been pooled into one.

#### 4.5 Person, Environment and Occupation Characteristics of Sample

Using the PEO model as an organizational framework, the characteristics of the sample related to person, environment, and occupation are presented in Tables 15 through 17 (starting on page 83). In addition to reporting the means and standard deviations for each characteristic, comparisons were made between those whose main work was unpaid versus paid, and between those who reported work limitations secondary to arthritis versus those not limited.

Characteristics of the person are summarized in Table 15. Those identifying themselves as mainly unpaid workers were, on average, older than paid workers. The proportion of women was greater among unpaid workers than paid workers. Unpaid workers reported slightly but significantly lower physical function than paid workers, as measured by both the HAQ and the physical function scale of the SF-36. Compared to paid workers, unpaid workers reported significantly less confidence in their ability to do everyday activities (lower self efficacy function scores), and were more satisfied with the balance of time they spent on work, self care, leisure and rest (occupational balance).

Differences in age, gender distribution, educational level and disease duration were not significant when the 'work limited' group was compared with the 'not limited' group (Table 15). However, there were several other differences between these two groups. Participants who reported work limitations reported significantly lower functional status, poorer general health, lower physical function, more role limitations due to physical health restrictions, more limitations in social function, more bodily pain, and less energy (more fatigue) than did those who were working as many or more hours than they would like. Further, the group with work limitations reported significantly lower self efficacy (all three subscales), and less occupational balance. In short, of all the health and functional status variables reported in Table 15, the only exceptions to poorer status on the part of the 'work limited' group were mental health and role limitations due to emotional health, which were not significantly different than the mean scores reported by the 'not limited' group.

Among the environment characteristics (Table 16), there were no significant differences between comparison groups (paid and unpaid workers, work limited and not limited).

Table 17 displays descriptive data for occupation characteristics. Unpaid workers rated their work tasks as requiring less skill discretion, more decision authority, less psychological demand and less isometric physical demand than did paid workers. Those whose work was limited by their RA rated their work as having less skill discretion and lower psychological demand than those whose work was not limited by RA.

The proportion of paid workers in each of four job classifications is in Table 18. This analysis is limited to the 143 respondents who rated paid work characteristics (the 127 who stated paid work as their main form of work, and 16 unpaid workers who gave two job titles and rated the attributes of both unpaid and paid work). There is no difference in the distribution of job classifications between those limited and not limited by their arthritis.

Additional descriptive characteristics (those not treated as explanatory variables in the main analysis) are in Table 19. Differences in disease status variables between paid and unpaid workers were not significant. Those who reported work limitation due to RA reported more active disease, more pain, and more fatigue than those who stated they worked as many or more hours than they would like. Unpaid workers had a larger proportion of lower household incomes than did paid workers, and those not limited by RA tended to be skewed toward higher incomes while those limited by RA were more evenly distributed across the four income categories.

#### Table 15. Person Characteristics.

Means (standard deviations), or counts (proportions), for all participants, and for two comparison groups.

Variable	range of	All	Unpaid	Paid	$p^1$	Limited	Not	$p^2$
	reported	Subjects	Workers	Workers		by RA	Limited	
er dage – en ande	values	n = 239	n = 96	n = 127		n = 72	n = 167	
Demographics:	10.55		[.]					
age	18-66	50.31	52.2	47.7	.001	51.5	49.8	.35
·		(12.71)	(10.8)	(9.2)		(10.4)	(10.2)	
gender	male	45	8	31	.002	14	31	.86
		(19%)	(8%)	(24%)		(19%)	(19%)	
	female	194	88	96		58	136	
	Tornaro	(81%)	(92%)	(76%)		(81%)	(81%)	
education	no	133	47	76	.21	39	94	.67
level. ³		(57%)	(52%)	(60%)		(55%)	(58%)	
post secondary		( )						
graduate	yes	100	44	50		. 32	68	
·	•	(43%)	(48%)	(40%)		(45%)	(42%)	•
disease	1-50	12.7	13.9	11.1	.03	13.3	12.4	.52
duration		(9.6)	(10.5)	(8.5)		(10.0)	(9.5)	
Health Assessme	nt Question	naire (HAQ)	•			· · · · · · · · · · · · · · · · · · ·	· · · · · · · · · · · · · · · · · · ·	
functional	0-2.38	0.46	0.51	0.40	.05	0.71	0.35	<.001
status		(0.43)	(0.44)	(0.39)		(0.44)	(0.38)	
Self Efficacy Sca	les (SES):							
self efficacy	10-100	55.2	54.5	56.8	.23	49.7	57.6	.01
pain		(21.9)	(23.0)	(20.2)		(23.3)	(20.9)	
self efficacy	10-100	70.4	66.1	74.2	.005	57.2	76.1	<.001
function		(24.7)	(26.9)	(21.7)		(26.2)	(21.8)	
self efficacy	10-100	63.7	65.5	62.9	.62	58.4	66.0	.009
symptoms		(20.5)	(20.2)	(20.6)		(20.8)	(20.0)	
Health Status (S.	F-36):							
general health	5-25	16.1	15.8	16.4	.18	14.3	16.9	<.001
		(4.6)	(4.8)	(4.3)		(4.9)	(4.2)	
physical	10-30	20.8	20.1	21.5	.004	17.7	22.2	<.001
function		(5.3)	(6.1)	(4.5)		(4.6)	(5.0)	
role: physical	4-8	5.9	5.65	6.04	.10	5.10	6.2	<.001
		(1.7)	(1.65)	(1.64)		(1.46)	(1.6)	
role: emotional	3-6	5.2	5.4	5.2	.18	5.1	5.3	.27
		(1.7)	(1.1)	(1.1)		(1.2)	(1.1)	
social function	2-10	7.8	7.8	7.8	.75	7.0	8.1	<.001
		(2.1)	(2.1)	(2.0)		(2.1)	(2.0)	
bodily pain	2-12	7.0	6.9	7.1	.18	5.9	7.5	<.001
		(2.1)	(2.0)	(2.1)		(1.7)	(2.0)	
vitality	4-24	13.3	13.1	13.4	.43	11.5	14.0	<.001
		(4.5)	(4.8)	(4.8)		(4.4)	(4.4)	
mental health	9-30	23.7	24.2	23.4	.30	23.3	23.9	.38
		(4.4)	(4.2)	(4.6)		(4.4)	(4.4)	
occupational	1-10	6.08	6.59	5.72	.007	5.57	6.29	.02
balance		(2.24)	(2.32)	(2.09)		(2.11)	(2.26)	

¹Refers to t-test or Chi² comparing unpaid workers to paid workers. ²Refers to t-test or Chi² comparing participants whose work is limited by their RA to those not limited. ³Six participants omitted a response to the question on educational level.

#### Table 16. Environment Characteristics.

Means (standard deviations), or counts (proportions), for all participants, and for two comparison groups.

Variable	range of reported	All Subjects p = 239	Unpaid Workers	Paid Workers n = 127	<b>P</b> ¹	Limited by RA n = 72	Not Limited n = 167	$p^2$
Work Environmen	t:		II.=.90	 		$\Pi = I/2$	<u>п</u> —107	
co-worker support	1-16	12.1 (2.0)	12.1 (2.3)	12.2 (1.8)	.74	12.2 (2.2)	12.1 (2.0)	.64
supervisory support 3 (n = 101)	8-19		not applicable	13.2 (2.1)	n/a	14.1 (2.0) n = 18	$ \begin{array}{r} 13.1 \\ (2.0) \\ n = 83 \end{array} $	.06
commuting difficulty 3 (n = 125)	2-10		not applicable	8.3 (2.2)	n/a	8.3 (2.4) n = 21	8.3 (2.2) n = 104	.96
Social Environmen	nt:				-	*****		
social support, significant other	1-7	5.7 (1.6)	5.8 (1.6)	5.7 (1.5)	.66	5.48 (1.76)	5.80 (1.53)	.15
social support, family	1-7	5.5 (1.6)	5.6 (1.6)	5.4 (1.5)	.23	5.23 (1.74)	5.54 (1.50)	.16
social support, friends	1-7	5.3 (1.6)	5.5 (1.5)	5.2 (1.5)	.16	5.26 (1.65)	5.31 (1.49)	.84
marital status, married/partnered	yes	183 (77%)	74 (77%)	98 (77%)	1.00	21 (29%)	35 (21%)	.19
	no	56 (23%)	22 (23%)	29 (23%)		51 (71%)	132 (79%)	
household size ⁴ total size	1-6	2.7 (1.3)	2.7 (1.2)	2.8 (1.4)	.72	2.5 (1.1)	2.8 (1.4)	.09
adults ≥18	1-6	2.3 (0.9)	2.2 (0.9)	2.3 (1.0)	.32	2.3 (0.9)	· 2.3 (1.0)	.36
children <18	0-4	0.5 (0.9)	0.5 (0.9)	0.5 (0.9)	.66	0.4 (0.6)	0.5 (1.0)	.08

¹Refers to t-test or Chi² comparing unpaid workers to paid workers.
 ²Refers to t-test or Chi² comparing participants whose work is limited by their RA to those not limited.
 ³Only 101 paid workers had work supervisors, and 125 commuted regularly to work.
 ⁴ Five participants omitted questions on household size and composition.

#### Table17. Occupation Characteristics

Variable	range of reported values	All Subjects n = 239	Unpaid Workers n = 96	Paid Workers n = 127	<b>p</b> ¹	Limited by RA n = 72	Not Limited n = 167	<i>p</i> ²
skill discretion	12-40	26.8 (5.1)	24.5 (5.2)	28.6 (4.4)	<.001	25.5 (5.2)	27.3 (4.9)	.01
decision authority	12-48	37.1 (6.6)	38.1 (5.6)	36.1 (7.3)	.027	38.2 (5.3)	36.6 (7.0)	.10
psychological demand	18-72	43.3 (10.3)	38.7 (8.2)	47.4 (10.3)	<.001	39.4 (9.4)	45.1 (10.2)	<.001
physical demand, exertion	3-12	6.2 (2.0)	6.1 (1.6)	6.4 (2.4)	.26	5.8 (1.9)	6.4 (2.1)	.06
physical demand, isometric	2-8	3.8 (1.3)	3.6 (1.1)	4.0 (1.4)	.02	3.7 (1.3)	3.8 (1.3)	.43

Means (standard deviations), for all participants, and for two comparison groups.

¹ Refers to t-test comparing unpaid worker to paid workers.
 ² Refers to t-test comparing participants whose work is limited by their RA to those not limited.

Job Classification	Paid Workers ¹ n = 143	Limited by RA $n=27$	Not Limited $n = 116$		
managers	20 (14%)	1 (4%)	19 (16%)	.34	
professionals	42 (29%)	10 (37%)	32 (28%)		
services	68 (48%)	13 (48%)	55 (47%)		
trades	13 (9%)	3 (11%)	10 (9%)		

#### Table 18. Occupation Characteristics: Job Classifications

Counts and (proportions) for 143 participants reporting on paid work and two comparison groups.

Includes 127 participants whose main occupation was paid work, plus 16 participants who 1 elected to report on their paid work characteristics in addition to their main, unpaid work.

 2  Chi² comparing the distribution of job classification categories for paid workers limited by RA to paid workers not limited by RA.

### Table 19. Additional Descriptive Characteristics: Global Disease Status and Income.

Variable	range of reported values	All Subjects n = 239	Unpaid Workers n = 96	Paid Workers n = 127	$p_{i_{i_{j_{i_{j_{i_{j_{i_{j_{i_{j_{i_{j_{i_{j_{i_{j_{i_{j_{i_{j_{i_{j_{i_{j_{i_{j_{i_{j_{i_{i_{i_{i_{i_{i_{i_{i_{i_{i_{i_{i_{i_$	Limited by RA n = 72	Not Limited n = 167	$p^2$
global disease activity	0-10	4.6 (2.8)	4.7 (2.8)	4.5 (2.7)	.48	5.4 (2.5)	4.3 (2.9)	.004
global pain	0-10	4.4 (2.7)	4.4 (2.7)	4.4 (2.7)	.91	5.2 (2.4)	4.1 (2.7)	.005
global fatigue	0-10	5.0 (2.7)	4.9 (2.8)	5.0 (2.6)	.65	6.1 (2.5)	4.5 (2.7)	<001
household income last $yr^3$ (n = 219)	<\$20,000	29 (13%)	16 (18%)	12 (10%)	.004	16 (24%)	13 (9%)	.001
(n 215)	\$20,001- 40,000	44 (20%)	21 (24%)	16 (14%)		18 (27%)	26 (17%)	
	\$40,001- 60,000	62 (28%)	27 (31%)	30 (25%)		16 (24%)	46 (30%)	
	>\$60,000	84 (38%)	23 (26%)	60 (51%)		16 (24%)	68 (44%)	

Means (standard deviations), or counts (proportions), for all participants, and for two comparison groups.

¹Refers to t-test or Chi² comparing unpaid workers to paid workers. ²Refers to t-test or Chi² comparing participants whose work is limited by their RA to those not limited. ³Twenty participants omitted the item on household income.

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#### 4.6 Associations Among Predictor Variables

Pearson correlation coefficients for all potential predictor variables are displayed in Table 20 (next page). There were several statistically significant associations, generally within expected clusters of variables. For example, the social support subscales of the MSPSS were highly correlated, as were several subscales of the SF-36 Health Survey. Because internal consistency is a desirable feature of an instrument, this was not unexpected. Likewise, household size correlated with its component parts, number of children and number of adults. In addition, various components of the self-efficacy scales, SF-36 scales, and HAQ score were moderately correlated with each other with the highest correlation coefficient being -0.70 (between self efficacy function and HAQ score). Age was not highly correlated with any other predictor variable (all but one correlation coefficient < 0.2); it was mildly correlated with psychological demand of work (r = -.27).

The effect of gender on potential predictors was tested by comparing mean values for men and women using t-tests. Only five variables were significantly different between men and women, and all mean differences were small in magnitude (see Table 21). Men rated their general health, vitality, and social support from friends slightly lower than did women. Men also reported lower self efficacy in managing arthritis pain than women, and among those who commuted to work, men rated the commute as slightly more difficult than did women.

Variable	Men Mean Score	Women Mean Score	p
self efficacy pain	49.2	56.6	.04
general health status	14.9	16.4	.05
vitality	12.0	13.6	.03
commuting difficulty	7.3	8.6	.02
social support from friends	4.6	5.4	.005

 Table 21. Gender Differences Among Potential Predictor Variables.

Variables:	1	2	т	4	5	9	7	8	6	10	11	12	13	14	15
<b>Person Characteristics:</b>															
1 Age	1.00	.18	.02	09	16	<u>5</u>	.08	19	05	60.	00.	08	.10	60.	.15
2 Disease Duration		1.00	.05	60.	08	.08	06	05	60.	90.	.06	6.	01	.07	0.
3 HAQ Disability score			1.00	42	70	43	35	70	48	22	47	60	42	18	31
4 Self Efficacy Pain				1.00	.53	.74	.46	.51	.37	.23	.41	.55	.51	.35	.35
5 Self Efficacy Function					1.00	.53	.36	.68	.33	.19	.42	.51	.35	.22	.29
6 Self Efficacy Symptom						1.00	.55	.50	.44	.41	.54	.55	.56	.51	.41
7 SF36 General Health							1.00	.45	.42	.44	.51	.48	<u>.</u>	.52	.41
8 SF36 Physical Function								1.00	.55	.25	.48	.64	.46	.22	.35
9 SF36 Role: Physical									1.00	.34	.60	.65	.53	.29	.33
10 SF36 Role: Emotional										1.00	.50	.32	.38	.58	.20
11 SF36 Social Function											1.00	.61	.58	.55	.39
12 SF36 Bodily Pain												1.00	.59	.32	.33
13 SF36 Vitality													1.00	.50	.43
14 SF36 Mental Health														1.00	.27
15 Occupational Balance															1.00
<b>Environment Characteristics:</b>															
16 CoWorker Support															
17 Supervisory Support															
18 Commuting Difficulty															
19 Social Sup Sig Other															
20 Social Support Family															
21 Social Support Friends															
22 Household Size															
23 HHSize: # Adults															
24 HHSize: #Children															
<b>Occupation Characteristics:</b>															
25 Skill Discretion															
26 Decision Authority															
27 Psychological Demand															
28 Physical Dem Isometric															
29 Physical Dem Exertion							-								
n=239, except #18 n=101 and #19	n=125.													/cont	inued

Table 20. Associations Among Potential Predictor Variables (Pearson Correlation Coefficients)

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Table 20. Associations Among Potential Predictor Variables (Pearson Correlation Coefficients), continued.

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$ \begin{array}{cccccccccccccccccccccccccccccccccccc$		.10	.00	õ		08	02	01	- 13	-0 <u>0</u>	10	.07	.03	04	8.5	13
$ \begin{array}{cccccccccccccccccccccccccccccccccccc$	$ \begin{array}{cccccccccccccccccccccccccccccccccccc$	90.	.18	.1.	, ,	.13	12	06	14	06	15	-11	07	11	<u>.</u> 50	- 12
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$ \begin{array}{cccccccccccccccccccccccccccccccccccc$	$ \begin{array}{cccccccccccccccccccccccccccccccccccc$	01	14	.1.		.03	.05	.06	.21	.08	.23	.16	.12	.08	-00	.10
$ \begin{array}{cccccccccccccccccccccccccccccccccccc$	$ \begin{array}{cccccccccccccccccccccccccccccccccccc$	.06(	2	.2		.04	.08	.03	.20	.18	.10	.12	.04	05	17	.03
$ \begin{array}{cccccccccccccccccccccccccccccccccccc$	$ \begin{array}{cccccccccccccccccccccccccccccccccccc$	.14 .2	2	Τ.	-	.14	.18	.18	01	08	-00	04	.14	19	17	11
$ \begin{array}{cccccccccccccccccccccccccccccccccccc$	$ \begin{array}{cccccccccccccccccccccccccccccccccccc$	.21 .13	$\sim$	.1	-	.16	.20	.18	.18	.16	.10	.11	.13	04	15	02
$ \begin{array}{cccccccccccccccccccccccccccccccccccc$	$ \begin{array}{cccccccccccccccccccccccccccccccccccc$	.05 .08	~~	.2		.08	.13	.11	.18	.07	.18	.07	.07	07	22	08
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$\begin{array}{cccccccccccccccccccccccccccccccccccc$	$\begin{array}{cccccccccccccccccccccccccccccccccccc$	.08 .21		5	~	.12	.16	.17	04	.01	07	04	.13	18	11	02
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$\begin{array}{rrrrrrrrrrrrrrrrrrrrrrrrrrrrrrrrrrrr$	$\begin{array}{cccccccccccccccccccccccccccccccccccc$	1.00 .45		5	•	.10	.15	.20	00.	04	.05	.10	.15	15	17	06
$\begin{array}{cccccccccccccccccccccccccccccccccccc$	$\begin{array}{cccccccccccccccccccccccccccccccccccc$	1.00		.1	10	60.	.23	.38	.06	.08	.01	90.	.24	36	21	20
$\begin{array}{rrrrrrrrrrrrrrrrrrrrrrrrrrrrrrrrrrrr$	$\begin{array}{cccccccccccccccccccccccccccccccccccc$			1.0(	~	.17	.07	.17	.10	90.	.08	01	.17	11	-0 <u>0</u>	05
$\begin{array}{cccccccccccccccccccccccccccccccccccc$	$\begin{array}{cccccccccccccccccccccccccccccccccccc$				1	00.	.75	.48	.19	.22	90.	03	<u>.</u>	.10	.01	.02
$\begin{array}{cccccccccccccccccccccccccccccccccccc$	$\begin{array}{cccccccccccccccccccccccccccccccccccc$					•	1.00	.61	.15	.18	<u>.</u> 04	01	.13	<u>00</u>	60	01
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$\begin{array}{cccccccccccccccccccccccccccccccccccc$	$\begin{array}{cccccccccccccccccccccccccccccccccccc$								1.00	.75	.70	.14	.05	.17	06	.06
1.00       .14       .09       .17       .08         1.00       .18       .37       .09      08         1.00       .10       .18       .17       .17         1.00       .10       .18       .17       .17         1.00       .10       .18       .17       .17         1.00       .10       .18       .17       .17         1.00       .10       .18       .17       .17         1.00       .10       .18       .17       .17         1.00       .10       .10       .42       .27         1.00       .42       .27       .100       .35	$\begin{array}{cccccccccccccccccccccccccccccccccccc$									1.00	.05	.07	01	60.	01	.01
1.00       .18       .37       .09      08         1.00      10      18      17         1.00       .42       .27         1.00       .42       .27	$\begin{array}{cccccccccccccccccccccccccccccccccccc$										1.00	.14	60.	.17	07	.08
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1.00 .42 .27 1.00 .35	1.00 .42 .27 1.00 .35 1.00										•		1.00	10	18	17
- 1.00 .35	1.00 .35 1.00													1.00	.42	.27
	1.00												•		1.00	.35

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n=239, except #18 n=101 and #19 n=125.

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#### 4.7 Factors Associated with Paid and Unpaid Work Hours: Univariate Analyses.

Age was significantly associated with fewer hours of unpaid, paid and total work, and women performed significantly more unpaid and less paid work than men (Table 22). There was no difference between men and women with regard to total work hours. Because age and gender demonstrated this potential to confound or modify the effect of other factors, both of these variables were included in all models. After adjusting for age and gender, the regression coefficients were calculated for each predictor variable in linear regression models for each of three outcomes: unpaid work hours, paid work hours and total work hours (Table 22).

*What factors were associated with unpaid work hours?* Statistically significant associations were found between greater hours of unpaid work and two *person* characteristics: reports of less pain, and having a post-secondary education. More unpaid work hours were also significantly associated with greater social support from the family, being married or partnered, and living in a larger household (three characteristics of the *environment*). And finally, with regard to *occupation* characteristics, more unpaid work hours were associated with reports of greater psychological demand and greater physical demand.

What factors were associated with paid work hours? Statistically significant associations were found between greater hours of paid work and reports of higher self efficacy (confidence in ability to do functional activities), better functional status (measured by either the HAQ or SF-36 physical function subscale), better social function, less pain and less satisfaction with occupational balance. None of the environment characteristics were significantly associated with hours of paid work. Of the four job classifications, being a manager was the only one significantly associated with more paid work hours. More paid work hours were also associated with work tasks rated as having greater psychological demand. Jobs with lower physical demand were associated with more hours of work at the p = .06 level.

*What factors were associated with total hours of work?* Every variable that was significantly associated with more unpaid or paid hours was subsequently associated with more total work hours, with two exceptions: occupational balance and support from the family. To summarize, person characteristics associated with more total work hours were greater self efficacy (function), better functional status, higher social function, less pain, and being a post-secondary graduate. Environment factors associated with more total work hours were being married or partnered and living in a larger household. When household size was further examined based on composition of adults and children under 18, the number of children (but not the number of adults) was significantly associated with more total work hours. Occupation characteristics associated with more total work hours were greater skill discretion, psychological demand, and isometric physical demand. Note that for some variables, the association with unpaid hours was negative while the association with paid hours was positive (and vice versa). The association of all variables with total work needs to be considered in light of these results. For this reason, there were no further analyses with total work as an outcome.

Table 22.	Univariate Linear Regression:	Effect of Candidate Variables on Hours of
	Unpaid Work, Paid V	Work and Total Work.

	Unpaid Work	Hours	Paid Work	Hours	Total Work	Hours
variable & possible score range	coefficient (std err)	p	coefficient (std err)	P	coefficient (std err)	P
age (yrs)	4 (.16)	.011	5 (.12)	<.001	9 (.17)	<.001
gender (female)	12.8 (4.1)	.002	-7.0 (3.2)	.03	5.8 (4.8)	.23
Person Characteristic	s:		· · ·		<u>.</u>	
educational level (post-secondary graduate)	9.3 (3.2)	.004	.61 (2.5)	.81	9.9 (3.6)	.007
disease duration (yrs)	.20 (.17)	.23	06 (.13)	.63	.14 (.19)	.47
functional status (HAQ, 0-3)	-5.3 (3.7)	.16	-7.3 (2.8)	.009	-12.5 (4.1)	.002

Age and gender are presented first; all subsequent regressions are adjusted for age and gender. n = 239.

.../continued

	Unpaid Worl	c Hours	Paid Work	Hours	Total Work	Hours
variable &	coefficient	р	coefficient	р	coefficient	р
possible score range	(std err)		(std err)	n para series de la compañía de la c	(std err)	eren hat.
self efficiency pain	01	87	10	08	11	10
(10-100)	.01	.07	(06)	.00	.11	.19
(10-100)	(.07)		(.00)		(.08)	
self efficacy	.11	.08	.14	.003	.26	<.001
function (10-100)	(.06)		(.05)		(.07)	
, , , , , , , , , , , , , , , , , , ,	· · /		( )		~ ,	
self efficacy	.062	.42	026	.66	.088	.31
symptoms (10-100)	(.08)		(.06)		(.09)	
			10		19	• •
general health	01	.98	.48	.07	.47	.23
(5-25)	(.35)		(.26)		(.39)	
physical function	37	22	50	nna	07	001
(10-30)	(301)	. 2 2	(23)	.007	(33)	.007
(10.50)	(		(.25)		()	
role: physical	40	.68	1.3	.07	.93	.29
(4-8)	(.95)		(.72)		(1.1)	
					. ,	
role: emotional	05	.97	1.1	.33	1.0	.53
(3-6)	(1.4)		(1.1)		(1.6)	
social function	.88	.25	1.57	.007	2.44	.005
(2-10)	(.77)		(.58)		(.86)	
hodily nain	1 66	03	1 2 2	025	3.0	001
$(2_12)$	(.77)	.05	(58)	.025	(85)	.001
(2-12)	(.77)		(.50)		(.05)	
vitality	.29	.42	.29	.28	.58	.15
(4-24)	(.35)		(.27)		(.40)	
mental health	.27	.46	17	.54	.43	.29
(5-30)	(.36)		(.27)		(.40)	
occupational	.68	.35	-1.20	.027	53	.52
balance (1-10)	(.72)		(.54)		(.81)	
Environment Charget	anistias					
co-worker support	- 46	56	- 17	.77	- 63	48
(6-24)	(.78)		(.60)	.,,	(.88)	.70
(0 - 1)	(1, 0)		(100)		(100)	
supervisory support	n/a		73	.37	n/a	
n = 101, (5-20)			(.81)			
commuting	n/a		03	.96	n/a	
difficulty, n = 125			(.68)		·	
(1-10)						

# Table 22. Univariate Linear Regression: Effect of Candidate Variables on Hours of<br/>Unpaid, Paid and Total Work (continued).

.../continued

	Unpaid Worl	k Hours	Paid Work	Hours	Total Work	Hours
variable &	coefficient	p	coefficient	р	coefficient	p
possible score range	(std err)		(std err)		(std err)	
	1.00	27	(2)	4.1	1 70	10
social support,	1.09	.27	.62	.41	1.70	.12
(1,7)	(.98)		(.75)		(1.10)	
social support	2.00	045	14	85	2 14	06
family (1-7)	(.99)	.045	(.76)	.05	(1.12)	.00
<b>j</b> (= · )	()					
social support,	.43	.68	47	.55	04	.97 •
friends (1-7)	(1.1)		(.8)		(1.2)	
marital status	7.70	.039	4.2	.14	11.9	.005
(married/partnered)	(3.7)		(2.8)		(4.2)	
household size	5 10	< 001	08	04	5.2	001
$(1_6)$	(1 3)	<b>\.001</b>	(1.0)	.94	(1.5)	.001
(1-0)	(1.5)		(1.0)		(1.5)	
# adults	-1.24	.48	1.04	.43	19	.92
	(1.73)		(1.32)		(1.96)	
# children	13.90	<.001	-1.28	.42	12.64	<.001
	(1.88)		(1.59)		(2.20)	
	• .•				<b>i</b>	
Occupation Character	$\frac{110}{100}$					
skill discretion	n = 110	62	n = 143	36	n = 239	01
$(12_48)$	.24	.02	23	.50	.92	.01
(12-40)	(.+0)		(.27)		(.55)	
decision authority	.18	.71	.14	.49	.17	.52
(12-48)	(.47)		(.19)		(.27)	-
( )						
psychological	1.0	. <i>001</i>	.36	.005	.76	<.001
demand (18-72)	(.30)		(.12)		(.17)	
physical demand	4.0	.11	25	.79	3.27	.02
isometric (2-8)	(2.5)		(.95)		(.89)	
nhysical domand	5 76	001	1 1 5	06	1 20	10
evertion (3-12)	(1.65)	.001	-1.15	.00	( 89)	.10
exertion (J-12)	(1.05)		(.00)		(.09)	

## Table 22. Univariate Linear Regression: Effect of Candidate Variables on Hours of Unpaid, Paid and Total Work (continued).

¹ Work characteristics were rated for respondents' main type of work. Some respondents elected to rate work characteristics for both paid and unpaid work. Thus, n = 110 for unpaid work, and n = 143 for paid work. For total work hours, n = 239, and the ratings for the respondents' main work were used.

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#### Table 23. Job Classification as a Predictor of Paid Work Hours.

Regression coefficients (standard error) and p-values from univariate linear regression using service workers as the reference category. Adjusted for age and gender. N=143 paid workers.

Job type	Regression coefficient	Standard error	р р
managers	10.57	4.22	.01
professionals	.02	3.27	.99
trades	2.67	5.63	.64

#### 4.8 Factors Associated with Work Satisfaction: Univariate Analyses

Univariate analyses for all predictors with work satisfaction as the outcome are presented in Table 24. Because neither age nor gender were associated with satisfaction with work performance, the analyses for the other predictors were not adjusted. Better functional and health status (as measured by all SF-36 subscales), greater occupational balance, more supervisory support and greater skill discretion of the work were significantly associated with higher work satisfaction.

variable & possible score range	coefficient (std err)	p	variable & possible score range	coefficient (std err)	p
age (yrs)	001 (.01)	.92	occupational balance (0-10)	.47 (.06)	<.001
gender (female)	.13 (.40)	.74	co-worker support (JCQ, 6-24)	.05 (.08)	.49
educational level (post-secondary graduate)	.06 (.32)	.86	supervisory support, n = 101 (JCQ, 5-20)	.25 (.11)	.03
disease duration (yrs)	.01 (.02)	.74	commuting difficulty, n = 125 (1-10)	.07 (.10)	.50
functional status (HAQ, 0-3)	-2.30 (.33)	<.001	social support, significant other (MSPSS, 1-7)	.001 (.10)	.99
self efficacy pain (10-100)	.05 (.006)	<.001	social support, family (MSPSS, 1-7)	.12 (.10)	.24
self efficacy function (10-100)	.05 (.005)	<.001	social support, friends (MSPSS, 1-7)	.14 (.10)	.16
self efficacy symptoms (10-100)	.06 (.007)	<.001	marital status (married/partnered)	30 (.37)	.42
general health (SF-36, 5-25)	.21 (.03)	<.001	household size (1-6)	14 (.12)	.25
physical function (SF-36, 10-30)	.22 (.03)	<.001	# adults	09 (.17)	.58
role: physical (SF-36, 4-8)	.51 (.09)	<.001	# children	21 (.18)	.25
role: emotional (SF-36, 3-6)	.54 (.13)	<.001	skill discretion (JCQ, 12-48)	.09 (.03)	<b>.004</b> .
social function (SF-36, 2-10)	.48 (.07)	<.001	decision authority (JCQ, 12-48)	.03 (.02)	.21
bodily pain (SF-36, 2-12)	.52 (.07)	<.001	psychological demand (JCQ, 18-72)	.01 (.02)	.53
vitality (SF-36, 4-24)	.22 (.03)	<.001	physical demand isometric (JCQ, 2-8)	20 (.12)	.10
mental health (SF-36, 5-30)	.13 (.03)	<.001	physical demand exertion (JCQ, 3-12)	01 (.08)	.88

Table 24.	<b>Univariate Linear</b>	<b>Regression:</b>	Effect of	<b>Candidate</b>	Variables on	Work Satisfaction	, n=239.

#### 4.9 Predicting Hours of Paid and Unpaid Work: Multivariable Models

*What model best predicts hours of unpaid work?* The analysis was limited to the 110 respondents who rated unpaid work characteristics (96 'unpaid workers' plus 14 'paid workers' who completed work characteristic items for both paid work and unpaid work, using their unpaid work ratings). The results of the multiple regression analysis with the eight *a priori* variables are in Table 25. In this initial model, younger age, less pain, more social support from family, and higher physical demand (exertion) of the work were strongly associated with unpaid work hours. Using a forward stepwise procedure (Table 26) these four variables remained significant and explained 25% of the variance in unpaid work. They were retained for subsequent model building.

In the systematic trial adding, in turn, each potential explanatory variable to the four already identified, six variables added at least 2% to the R² from the previous model. These were educational level, self efficacy (pain subscale), physical role limitations (SF-36 subscale), marital status, number of children in the household, and psychological demand of the work. A final model was generated using these six variables together with the four identified in Table 26 (see Table 27). The final model predicted 43% of the variance in unpaid hours of work, and contained five predictors. More support from family, more children in the household, work that was rated as physically and psychologically demanding and being a post-secondary graduate were associated with more hours of unpaid work. Pain and age, significant in the initial model, were pushed out by the addition of new variables. Role limitations due to physical health status, self efficacy pain, and marital status, while independently adding explanatory power to the initial model, did not contribute significantly when entered as part of the final group of candidate variables.

Variables	Coefficients (Unstandardized	Std Error	Coefficients (Standardized)	t	р
intercept	-10.65	31.45		34	.74
age (years)	61	.24	22	-2.50	.01
gender (female)	8.34	9.32	.08	.90	.37
lower functional status (HAQ)	4.42	7.49	.07	.59	.56
less pain (SF-36)	3.07	1.65	.20	1.85	.07
more family support (MSPSS)	3.32	1.61	.18	2.06	.04
higher physical demand (exertion) of work (JCQ)	5.44	1.67	.29	3.25	.002
more skill discretion of work (JCQ)	.18	.46	.04	.39	.70
more decision authority of work (JCQ)	16	.46	03	35	.72

# Table 25. Predicting Unpaid Work Hours: Linear Regression Model Containing All *a priori* Variables.

 $R^2 = .26$ 

## Table 26. Predicting Unpaid Work Hours: Model, After Forward Stepwise Procedure with All *a priori* Variables.

Variables	Coefficients Std Error Coefficients t (Unstandardized) (Standardized)				р	
intercept	4.35	20.37		.21	.83	
age (years)	64	.24	23	-2.68	.009	
less pain (SF-36)	2.66	1.31	.18	2.04	.04	
more family support (MSPSS)	2.97	1.54	.16	1.92	.06	
higher physical demand (exertion) of work (JCQ)	5.30	1.62	.29	3.27	.001	

 $R^2 = .25$ 

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# Table 27. Predicting Unpaid Work Hours: Final Model After Consideration of All Potential Predictors.

Variables	Coefficients (Unstandardized	Std Erro	or Coefficients (Standardized)	t	р
intercept	-40.36	14.15		-2.85	.005
more family support (MSPSS)	2.46	1.40	.14	1.76	.08
higher physical demand (exertion) of work (JCQ)	4.71	1.45	.25	3.25	.002
more children in household	12.12	2.42	.40	5.01	<.001
higher psychological demand of work (JCQ)	.71	.27	.21	2.60	.01
educational level (post secondary graduate)	8.43	4.58	.14	1.84	.07

 $R^2 = .43$ 

What model best predicts hours of paid work? The analysis was limited to the 143 respondents who rated paid work characteristics (127 'paid workers' plus 16 'unpaid workers' who completed work characteristic items for both paid work and unpaid work, using their paid work ratings). The results of the multiple regression analysis with the 8 a priori variables are in Table 28. From this cluster, none were significantly associated at the level of p < .05. When entered stepwise (Table 29), gender and pain emerged as predictors of paid work hours (p = .06 and .02, respectively). In the systematic trial adding, in turn, each potential explanatory variable to pain and gender, four new variables added at least 2% to the R² from pain and gender: occupational balance, social function, psychological demand of the work, and managerial job type. Using a forward stepwise procedure with these six variables, the result was a model explaining 25% of the variance in paid work hours. See Table 30. All six remained in the final model. More paid work hours were associated with being male, less pain, better social function, work tasks rated as more psychologically demanding, having a managerial job, and lower satisfaction with occupational balance. (Recall that occupational balance refers to perceived balance among paid and unpaid work, self care, leisure and rest).

Variables	Coefficients (Unstandardize	Std Error d)	Coefficients (Standardize	s t d)	р
intercept	49.80	20.00		2.49	.01
age (years)	06	.16	04	41	.68
gender (female)	-6.09	3.53	15	-1.72	.09
lower functional status (HAQ)	-3.28	4.30	08	76	.45
less pain (SF-36)	.89	.88	.11	1.01	.32
more co-worker support (JCQ)	58	.79	06	74	.46
higher physical demand (exertion) of work (JCQ)	-1.01	.65	14	-1.55	.12
more skill discretion of work (JCQ)	32	.30	10	-1.08	.28
more decision authority of work (JCQ)	.17	.21	.07	.79	.43

Table 28.P	redicting Paid	Work Hours: I	Linear Regression	Model Containing A	ll <i>a priori</i> Variables.
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 $R^2 = .10$
Variables	Coefficie (Unstandar	ents Std Error lized)	Coefficie (Standardiz	nts t zed)	р
intercept	23.55	5.66		4.16	<.001
gender (female)	-6.24	3.30	16	-1.89	.06
less pain (SF-36)	1.61	.67	.20	2.40	.02
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# Table 29. Predicting Paid Work Hours: Model, After Forward Stepwise Procedure with All *a priori* Variables.

 $R^2 = .07$ 

Table 30. Predicting Paid Work Hours: Final Model After Consideration of All Potential Predictors.

Variables	Coefficients (Unstandardized	Std Error	Coefficients (Standardized)	t	р
intercept	1.52	8.91		.17	.87
gender (female)	-6.03	3.05	15	-1.98	.05
less pain (SF-36)	1.27	.75	.16	1.69	.09
higher social function (SF-36)	2.08	.78	.25	2.69	.008
greater psychological demand of work (JCQ)	.39	.12	.26	3.33	.001
greater occupational balance (1-10 scale)	-1.90	.62	24	-3.06	.003
job classification (managerial)	8.54	3.67	.18	2.33	.02

 $R^2 = .25$ 

#### 4.10 Predicting Work Limitations Secondary to Arthritis

A secondary outcome measure in the study was whether or not one worked less than one wanted to as a result of arthritis (or "work limitation"). Seventy-three participants indicated their work was limited. Logistic regression analysis, following the same process as that outlined for linear regression, was used to identify factors associated with work limitation. The full sample of 239 is included in the analysis. From the initial cluster of 8 variables, lower functional status, more pain, less skill discretion and greater decision authority were significantly associated with work limitation. Age, gender, physical demand of the work, and co-worker support were not, so they were removed from subsequent analyses. See Table 31. When each of the remaining variables were added one at a time to a model containing functional status, pain, skill discretion, and decision authority, three additional variables were significantly associated with work limitation: psychological demand, physical function (SF-36), and the job classification of household workers. Psychological demand and job classification were added to the four significant predictors from the initial model. Since the HAQ and SF-36 physical function subscale were highly correlated and measured the same construct, only HAQ was retained in this step. The final results are shown in Table 32. Skill discretion and decision authority were no longer significant predictors of work limitation. Work limitation was associated with lower functional status, more pain, less psychologically demanding work, and being a household worker. Eighty percent of the sample was correctly classified by the final model.

Variables	Odds Ratio	95% confidence interval
age (years)	1.00	.97 - 1.04
gender (female)	.87	.38 – 1.95
lower functional status (HAQ)	3.66	1.44 - 9.30
less pain (SF-36)	.74	.6092
more co-worker support (JCQ)	1.01	.87 - 1.19
higher physical demand, exertion (JCQ)	.87	.74 - 1.04
greater skill discretion of work (JCQ)	.92	.8799
greater decision authority of work (JCQ)	1.07	1.01 - 1.13

Table 31. Odds Ratios for Variables in Initial Model Predicting Work Limitation (a priori variables).

Table 32. Odds Ratios for Variables in Final Model Predicting Work Limitation.

Variables	Odds Ratio	95% confidence interval
lower functional status (HAQ)	3.88	1.46 - 10.32
less pain (SF-36)	.73	.5991
greater skill discretion of work (JCQ)	1.01	.94 - 1.09
greater decision authority of work (JCQ)	1.05	.99 - 1.11
job classification, household workers	3.18	1.48 - 6.85
more psychological demand (JCQ)	.96	.9299

#### 4.11 Predicting Work Satisfaction

The other secondary outcome measure was satisfaction with performance of main work activities (or work satisfaction). The results of the exploratory analysis are in Table 33. All 239 subjects were included in this analysis. There was an association between increased work satisfaction and higher levels of self efficacy (i.e., confidence in managing arthritis symptoms and functional activities), greater sense of occupational balance, higher skill discretion associated with the work, and smaller household size.

Variables	Coefficients (Unstandardized)	Std Error	Coefficients (Standardized)	t	р
intercept	.04	.82		.05	.96
higher self efficacy, symptoms (SES)	.03	.007	.25	3.88	<.001
higher self efficacy, function (SES)	.03	.006	.28	4.57	<.001
greater occupational balance (1-10)	.28	.06	.26	4.53	<.001
more skill discretion of work (JCQ)	.07	.025	.15	2.89	.004
larger household size	23	.096	12	-2.36	.02

Table 33. Predictors of Satisfaction with Performance of Main Work Activity, n = 239.

 $R^2 = .40$ 

#### 4.12 Model Verification

Residual analyses were used to identify influential cases and to verify that model assumptions had not been violated for each of the final models predicting paid and unpaid work hours, work satisfaction, and work limitation.

As an example, the scatterplot for predicted values and standardized residuals for the model predicting unpaid work hours is presented in Figure 7. There was no suggestion that underlying assumptions had been violated. Casewise diagnostics identified one case as potentially influential, with a standardized residual of 3.9. When this case was removed, the

variance in unpaid work hours explained by the final model remained unchanged at 43%. Similarly, for paid work, the scatterplot of predicted values and standardized residuals did not suggest any violation of model assumptions. No potentially influential cases were identified in the paid work model.





For the work satisfaction model, three cases had standardized residuals greater than 3 standard deviations. When these three cases were removed, the variance in work satisfaction explained by the model improved from 40% to 46%.

For the work limitation model, eight potentially influential cases were identified with standardized residuals exceeding two standard deviations. Seven of these cases identified themselves as limited by their RA, one was not limited. When logistic regression was repeated with these eight cases removed and the same co-variates as listed in the final model (Table 32), the results remained essentially the same. The odds ratios for functional status (HAQ), pain, and job type (household worker) became more pronounced. The proportion of cases correctly classified by the model improved slightly, from 80% to 84%.

#### 4.13 Post-hoc Analyses to Investigate Effect Modification

Separate analyses for men and women were considered, but the number of men was considered too small to do so. The multiple linear regression analysis predicting unpaid work hours had only 9 men. The analysis repeated with women only (n = 101) had an outcome almost identical to that for the entire sample, with no substantive changes in the significant predictors, regression coefficients, or  $R^2$ . Interaction terms using gender were not considered appropriate in this model, given only 9 men.

There were 112 women and 31 men in the multiple linear regression analysis predicting paid work hours. One of the predictors in the final model was gender. When a separate analysis was done for women only, the model had two fewer predictors. One was gender, (no longer relevant in a single gender analysis), and the other was pain. The regression coefficients remained similar for psychological demand, social function and occupational balance; the coefficient for managerial job type increased, and all of these predictors remained significantly associated with the outcome of paid work. The regression coefficient for pain decreased from 1.27 to 0.16 in the women only analysis, and was no longer significant (p = .12). It was considered significant in the original analysis, at p = .09, since the criterion was set at .10 for accepting explanatory variables.

Because there were 8 variables in the *a priori* cluster and 6 in the final model for paid work, the sample of 31 men was considered too small to conduct a similar 'men only' analysis, or to create meaningful interaction terms using gender.

For the model predicting unpaid work, number of children in the household was a strong predictor. However, 70 of the 110 participants in this analysis did not have children. Using the variables in the final model for unpaid work (Table 27), multiple linear regression analyses were repeated with two sub-groups: those with and without children (Tables 34 and 35). Because only 35 participants had children, the error is large in the analysis with this sub-group and the parameter estimates may be unstable. (Five respondents omitted the questions on household composition and were excluded from the analyses).

Variables	Coefficients (Unstandardized)	Std Error	Coefficients (Standardized)	t	р
intercept	-26.55	15.40		-1.72	.09
more family support (MSPSS)	1.99	1.37	.16	1.45	.15
higher physical demand (exertion) of work (JCQ)	3.99	1.63	.28	2.46	.02
more children in household	n/a				
higher psychological demand of work (JCQ)	.56	.29	.22	1.91	.06
educational level (post secondary graduate)	5.75	5.01	.13	1.15	.26

# Table 34. Variables from Final Model for Unpaid Work Entered into Analysis Restricted to Participants without Children, n = 70.

 $R^2 = .18$ 

 Table 35. Variables from Final Model for Unpaid Work Entered into Analysis

 Restricted to Participants with Children, n = 35.

Variables	Coefficients (Unstandardized)	Std Error	Coefficients (Standardized)	t	_ p
intercept	-118.89	41.43		-2.87	.01
more family support (MSPSS)	7.19	4.39	.24	1.64	.11
higher physical demand (exertion) of work (JCQ)	6.89	3.18	.34	2.17	.04
more children in household	18.10	5.65	.47	3.21	.003
higher psychological demand of work (JCQ)	1.12	.61	.28	1.85	.08
educational level (post secondary graduate)	20.48	10.41	.29	1.95	.06

 $R^2 = .47$ 

Univariate associations for the two groups (respondents with and without children) were also assessed. In univariate analyses, educational level, pain, and household size, which were significantly associated with unpaid work hours for the full sample of unpaid workers, were not significant for the sub-group without children at home. Disease duration, which was not significantly associated with unpaid work for the full sample (p = .23) was significantly associated with unpaid work for the sub-group with no children (p = .03). Social support from family, psychological demand and physical demand of the work were significant univariate predictors in both groups.

Because the presence of children appeared to influence the prediction of unpaid work, the entire model building process was repeated for the group of unpaid workers without children. The final multiple regression model is in Table 36. Higher physical demand of the work and more social support from the family remained significantly associated with more hours of unpaid work. Psychological demand and educational level did not enter the final model for participants without children at home. Two new variables entered the model: decision authority and disease duration. More hours of unpaid work were associated with reports of less decision authority of work and longer disease duration.

Variables	Coefficient (Unstandardiz	s Std Error zed)	Coefficien (Standardiz	ts t ed)	р
intercept	10.53	19.60		.54	.59
higher physical demand (exertion) of work (JCQ)	4.39	1.55	.30	2.83	.006
more family support (MSPSS)	3.07	1.35	.25	2.27	.03
more decision authority of work (JCQ)	81	.44	21	-1.85	.07
disease duration (years)	.53	.21	.28	2.56	.01

Table 36. Predicting Unpaid Work Hours: Final Model for Participants without Children, n = 70.

 $R^2 = .25$ 

The multiple logistic regression analysis conducted to predict work limitation used the entire sample of 239. The predictors of work limitation may vary for unpaid workers compared to paid workers, so the analysis was repeated with these two sub-groups, using the co-variates from the final model predicting work limitation (from Table 32). The odds ratios for these variables in the full sample, unpaid workers, and paid workers are compared in Table 37.

Variables	Full Sample	Unpaid Workers	Paid Workers
	n = 239	n = 110	n = 143
lower functional status (HAQ)	3.88	13.5	1.78
	(1.5 – 10.3)	(2.8 - 64.8)	(.50 – 6.4)
less pain (SF-36)	.73	.76	.82
	(.59 –.91)	(.55 – 1.0)	(.62 – 1.1)
greater skill discretion of work (JCQ)	1.01	.99	1.1
	(.94 – 1.1)	(.91 – 1.1)	(.96 – 1.2)
greater decision authority of work (JCQ)	1.05	1.0	1.1
	(.99 – 1.1)	(.95 – 1.1)	(.98 – 1.1)
job classification, household workers	3.18 (1.5 – 6.9)	n/a	'n/a
more psychological demand (JCQ)	.96	.97	.97
	(.92 –.99)	(.92 – 1.0)	(.93 – 1.0)

# Table 37. Odds Ratios (95% Confidence Intervals) from Logistic Regression Predicting Work Limitation Due to RA.

The most striking difference resulting from the sub-group analyses was in functional status, as measured by the HAQ. The odds ratio for functional status tripled for unpaid workers compared to what it was for the full sample. For paid workers, the odds ratio for functional status declined, and was no longer significantly associated with work limitation. The remaining predictors had approximately the same odds ratios for unpaid and paid workers as they did for the full sample. Among the 110 unpaid workers, 48 stated their work was limited by RA, compared to 27 of the 143 paid workers.

Job type was not applicable in the separate analyses because all unpaid workers and none of the paid workers were classified as household workers. When job type, using the four classifications of paid work, was added to the model for paid workers, none of the types were significantly associated with the outcome of work limitation. However, the data suggested that managerial workers were less likely than service workers to report work limitation (OR = 0.2, 95% CI = .02, 1.8), while professionals and trades workers were more likely to report work limitation (professional OR = 1.2, 95% CI = .42, 3.7; trades OR = 1.97, 95% CI = .42, 9.3).

# Chapter V Discussion

The main purpose of the study was to predict participation in paid and unpaid work, and secondarily to identify factors associated with work limitation and satisfaction with work performance. Key findings from the multivariable analyses are summarized in Table 38. The candidate predictor variables were the same for each outcome, but those that were significant in each of the final models vary across the outcomes. The table helps make comparisons that were not so apparent when the results were examined one outcome at a time.

Characteristics of	more	more	greater	work limitation
tne:	paid work	unpaid work	work satisfaction	due to RA
Person	gender (male)			
	less pain			more pain
	higher social			
	function			
	less occupational		greater occupational	
	balance		balance	
		educational level		
		(post-sec grad)		
			greater self efficacy	
			(symptoms,	
			function)	
				lower functional
				status
Environment		more social support		
		(family)		
		more children	smaller household	
			size	
Occupation	more psychological	more psychological		less psychological
	demand	demand		demand
		more physical		
		demand		
			more skill	
			discretion	
	type of work			type of work
	(managerial)			(household)

 Table 38. Summary of Findings:

 Factors Associated with Paid and Unpaid Work, Work Satisfaction and Work Limitation.

For example, three predictors of paid work hours are similar to the risk factors for work limitation: pain, psychological demand and type of work. More pain is associated with both work limitation and fewer hours of paid work. The same trend was apparent for less psychologically demanding work. With regard to type of work, managers tended to work more paid hours, and household workers were more likely to report work limitations. It makes sense that some of the factors that predict greater participation in paid work would, in reverse direction, predict work limitation because these two outcomes represent opposite ends of a continuum of work. The present sample clearly responded to the work limitation question with paid work in mind. Their hours of unpaid work were not different from those without limitations, whereas their paid work hours were substantially less.

Occupational balance was associated with both paid work hours and work satisfaction. However, respondents who reported less occupational balance tended to work more, while those who reported greater occupational balance were also more satisfied with their work performance. Because occupational balance refers to satisfaction with time allocation, and because paid work hours tend to be obligatory and scheduled, it is not surprising that respondents with many paid work hours would find satisfactory occupational balance to be elusive. To some, it must seem as if there is rarely enough time to devote to self-care, family, or leisure, as long as paid work takes precedence in their weekly schedule. But, respondents who were able to spend time in paid and unpaid work, as well as self-care, leisure and rest, in a way that met their needs, reported greater satisfaction with their work performance. Perhaps this suggests that they had sufficient time to do their work in way that met their standards for a job well done. If pushed for time, or when there are competing demands on one's time, it may be more difficult to be satisfied with work performance. Additionally, if it begins to take longer to do work tasks as a result of physical impairments, satisfaction with performance may decline.

The results are explored in more detail below.

## 5.1 Representativeness of the Sample

The participants in the study were drawn from the community-based practices of six rheumatologists. This may partially explain why, as a whole, they are relatively more able (HAQ scores averaging 0.46) than samples selected for other studies of RA and work (e.g., 0.60 in Allaire et al., 1996; 1.03 in Wolfe & Hawley, 1998). Other studies recruited some or all of their participants from rheumatologists based in university-affiliated arthritis centres which may have a higher proportion of more challenging cases (Koehler & Koehler, 1981). This idea is supported by the HAQ scores obtained from the field-test participants, a mean of 1.07, from a sample of patients drawn from a university-affiliated arthritis center, half of whom had more severe RA. It is also possible, though, that only the "more able" among those invited to participate completed surveys. However, the respondents did not differ in age, gender or disease duration compared to the 30 patients who refused participation and provided basic demographic information (data not shown). And, the participation rates across physician offices were remarkably consistent. The sample was predominantly female, and resided in the Lower Mainland and Fraser Valley region of British Columbia. It included both household workers and people who were employed. Results can only be generalized to those with similar characteristics.

#### 5.2 Patterns of Work

Overall, participants engaged in an average of 47 hours of work in one week, 19 hours of paid work and 28 hours of unpaid work. Most respondents engaged in several types of work. Respondents categorized their main form of work based upon the hours spent doing it: those whose main form of work was paid employment reported more time in paid work, and those whose main form of work was unpaid reported more hours in household work and caregiving. The amount of work was associated with global disease status indicators, in ways that made sense. That is, people who reported more pain and fatigue engaged in fewer hours of household work. Given the discretionary nature of household work it is reasonable

that the work would be put off during times when arthritis symptoms were acute. The amount of paid work was not associated with global disease status indicators. This may reflect the obligatory nature of paid work, such that people go to work regardless of variations in pain and fatigue.

Compared to the general population of the same age in Canada, participants in the present study worked fewer hours overall. For men, this difference was mostly attributed to household work and paid work hours: men with RA worked approximately six and eight hours less per week in these two categories than men in the general population. Together, that represents a loss of one-and-a-half to two days of work per week, indicating that RA has a fairly substantial impact on work participation. The RA sample included just 45 men, so may not provide accurate estimates of hours worked by men with RA in general. Sixty-nine percent of the men with RA identified themselves as paid workers, the rest identified themselves as household workers or retired. The proportion of employed and retired men upon which the general population work hours are based is not known. Perhaps the differences in work hours arise from a higher rate of "early retirement" among men with RA compared to the general population. Certainly, the prevalence of work disability in previous studies of people with RA would support this explanation.

Women with RA reported about five fewer hours of household work and less than three fewer hours of paid work than did women in the general population. This difference is not as great as the difference noted for men, but still suggests that RA has an impact on hours of work. Both men and women with RA reported two fewer hours of volunteer work than adults without RA. Given the relatively few hours of volunteer work in a week for both groups, this difference is proportionately quite large. Declining or avoiding opportunities to engage in volunteer work may be an early sign of the impact of RA on unpaid work. Another possible explanation was offered by discussion group participants: participation in volunteer work was viewed as a threat to eligibility for disability pensions. Because only 15% of survey participants were receiving disability pensions, this seems insufficient to fully explain the relatively large difference in volunteer hours.

There were some interesting differences related to other areas of work. Men and women in the RA sample provided more care-giving hours than the general population; for women, it was more than twice as many hours (6.7 versus 3.0 hours per week). Men with RA also reported more hours spent on home maintenance and studying than the general population. Some or all of these differences may be due to the unique work patterns of the RA sample, which is not representative of all people with RA the way the General Social Survey sample may represent the Canadian population. However, when some categories of work are limited due to illness, perhaps people pursue types of unpaid work that are better matched to their abilities, find they have the time to do more of it, or take longer to do it. This would be a worthwhile question to ask in future research.

MacKinnon's (1992; MacKinnon et al., 1994) study is the only other investigation documenting hours of paid and unpaid work among people with RA. In her study the categories of unpaid work were slightly different, but the results permit some comparisons. The MacKinnon sample was from London, Ontario, and, being 75% female, with an average age of 50, was similar in composition to the respondents in the present study. (MacKinnon did not report disease duration or mean functional status scores). Adding her categories of market work, household/yard work, child care and studying to estimate total work, MacKinnon's sample worked an average of 37 hours compared to the present sample's 47 hours. Both paid and unpaid work hours were less, with MacKinnon's group spending 14.7 hours in paid work compared to the present sample's 18.6 hours, and 22.5 hours in unpaid work compared to 28 hours in the present sample. The difference in unpaid hours can be attributed to caregiving hours, because MacKinnon's sample reported 19 hours of household and yard work, which is similar to the present sample's household and home maintenance hours of 20. But the present sample spent an average of 6 hours in caregiving compared to 1.7 hours of childcare by MacKinnon's RA group.

Given that the present sample is characterized as "relatively able," they may have worked more than another group of subjects with RA because they had fewer physical limitations. It would have been useful to know the functional status of MacKinnon's sample to further explore these differences in patterns of work. The sampling process may partly explain the differences. Participants in MacKinnon's study were invited to participate by one of two rheumatologists at the University Hospital rheumatology clinic. Of those agreeing to participate, 92% of them completed the survey (similar to the 89% of returned surveys in the present study), but the number of patients invited to participate is not reported. Koehler and Koehler (1981) noted that university-affiliated clinics tended to receive a higher proportion of referrals for people with more severe disease than that observed in community-based samples.

#### 5.3 Differences Between Paid and Unpaid Workers

Unpaid workers were less satisfied with their work performance than were paid workers. This may be because the group of unpaid workers includes a larger proportion of people who reported work limitations secondary to RA (44% compared to 19%). It seems reasonable that if one must curtail work hours as a result of illness, one may also be dissatisfied with work performance. An alternative explanation is to suggest that unpaid work is inherently less satisfying than paid work. This may be true in some instances. But there are mundane and unsatisfying duties in both paid and unpaid work, just as there are duties that are highly valued in both. Further, the work satisfaction variable focused on performance and asked "how satisfied are you in your ability to perform your main work activity?" so the former explanation seems more likely than the latter.

Unpaid workers were, on average, older and consequently had RA for more years than paid workers. However, their functional status was very similar, whether measured by the HAQ (0.5 compared to 0.4) or the SF-36 physical function subscale (20 compared to 22). Where they differed was in their level of confidence about their functional capacity. The unpaid workers reported less self efficacy with regard to function than did paid workers. Again, it is tempting to relate this to the fact that the unpaid workers group had more participants who were working less than they wanted to because of their RA. Causal relationships are only a matter of speculation, and even the direction is not clear. Is the work

limitation a result of poor self efficacy (low confidence in functional skills), or is low self efficacy a result of not working as much as one wants?

Both paid and unpaid workers had stronger self efficacy with regard to function than they did with regard to managing pain or other symptoms, and the differences between groups on these two measures were very small (2 and 3 percent). In comparing participants limited by their RA to those not limited, the differences in self efficacy are more pronounced. The mean self efficacy function score for those limited by RA was 19% lower than for those not limited by arthritis. If self efficacy is the "cause" and work hours the "outcome" then it would be worthwhile to consider interventions aimed at improving self efficacy in order to improve work capacity. Efficacy-enhancing strategies have been shown to change behavior and improve arthritis symptoms (Lorig & Holman, 1993; Lorig et al., 1993); perhaps they can improve work outcomes as well.

Unpaid workers reported greater occupational balance than paid workers. That is, unpaid workers were more satisfied with the balance among occupations (unpaid work, paid work, self care, leisure, and rest). This supports the assumption that household work is more discretionary in nature: household workers have more autonomy to decide what tasks need doing and when to do them (Lombardi & Ulbrich, 1997). In contrast, paid workers have a large proportion of their time ascribed to their employment, and may not be able to find the time they wish to spend on other occupations. In reviewing the work characteristic variables, this idea is supported by unpaid workers ratings of decision authority, which were higher than those for paid workers. Decision authority was based on responses to items such as "My work allows me to make a lot of decisions on my own." Decisions may influence pace of work as well, and it may be possible to compress unpaid work into less time or do less of it and allow a better balance among different occupations. Paid work schedules are often based on clock time, so even if paid workers have a fair amount of decision authority, they are still expected to put in the requisite number of hours of work. This may prevent them from achieving what they perceive to be an ideal balance of time among work, self care, leisure and rest.

Three occupation characteristics were rated lower by unpaid workers than by paid workers: skill discretion, psychological demand, and physical demand (isometric). These results indicated that paid workers had more choice in deciding which skills to use at work, found their work more psychologically demanding, and their work required more static body positions than did unpaid workers. There was no difference in physical demand (exertion) ratings. This is the first time the JCQ has been used to measure unpaid work characteristics, so comparisons should be made cautiously. The JCQ was originally validated for a broad spectrum of paid jobs (Karasek et al., 1998) not for household and other forms of unpaid work. Nevertheless, the differences between paid and unpaid workers' work characteristics seem to match previous findings about the attributes of work in paid and unpaid contexts (Lombardi & Ulbrich, 1997). Lombardi and Ulbrich (1997), in a study of non-disabled women who were primarily paid workers or unpaid household workers, found greater decision latitude in household work, and greater psychological and physical demand in paid work. Reisine and colleagues (1987) offered an explanation for the differences, when they conceptualized homemaking "as a social role distinct from the paid worker role, without the role obligations attributed to paid employment such as scheduled work hours and tasks. Rather, it was assumed that homemakers' obligations varied considerably according to factors such as the stage in the family cycle and were more open to negotiation to accommodate personal preferences than were the demands of paid work." However, this was a theoretical statement, they did not attempt to measure work characteristics or compare them across paid and unpaid settings.

# 5.4 Factors Associated with Participation in Unpaid Work

Factors associated with hours of unpaid work were identified in both univariate and multivariable analyses. Only one person characteristic was associated with more hours of unpaid work, and that was level of education. Being a post secondary graduate was a significant predictor in both univariate regression and the final multiple regression model. Other characteristics of the person, specifically age, gender and perceived pain, were significant in the univariate analyses, but did not enter the final predictive model. Why

might higher educational level be associated with more hours of unpaid work? Perhaps because unpaid work included studying, volunteering and caregiving – people with higher education may engage in continuing education, may have more professional or parental volunteer opportunities, and may be more likely to read to children or otherwise create more unpaid work. Those with a post-secondary education may be more likely to have partners who are also highly educated, with higher paying jobs, which enable the partner with RA to stay home and assume more household responsibility. Interestingly, in Allaire and colleagues' study of homemakers, being a college graduate was associated with less household work (Allaire et al., 1991).

Environment characteristics that were associated with more hours of unpaid work were social support from the family and household size, particularly number of children. Number of children made the largest contribution to predicting hours of unpaid work in the final regression model: for each child under 18 in the household, unpaid work increased by about 12 hours per week. By comparison, for each unit of change on the MSPSS subscale for social support from family members, unpaid work increased by 2.5 hours. These are two quite different aspects of the environment. Having children creates more unpaid work, while social support enables more work to be done. Unpaid work included hours spent caregiving, which is naturally associated with having children, but children in the household probably increased the demand for other aspects of household work such as cleaning, cooking, shopping and laundry. Mothers do not need a regression analysis to conclude that children increase unpaid work. However, the finding that more social support from family members increased hours of unpaid work is interesting. Family support could be viewed from two perspectives: if family members are available to do the work, then their support may decrease the hours of unpaid work; on the other hand, in this study, having the support of family members may have enabled participants to do more unpaid work. As a study of association, not cause and effect, this can only be proposed as a hypothesis for future study.

Among the occupation characteristics studied, only two were significantly associated with hours of unpaid work. Increased physical demand (exertion) and increased psychological demand were associated with increased hours of unpaid work, in both

univariate and multivariable models. It is not readily apparent why work that is rated more physically demanding would be associated with more hours of unpaid work. Perhaps work is more likely to be rated as physically demanding when there is more of it to do. For unpaid work, the time spent doing it increases to meet the demands of the household, and as the demand increases perhaps perceived exertion increases. Or, because unpaid work can expand to fit the available time, it's possible that participants engaged in physically demanding work but did it more slowly. Those who work only a few hours might not consider their work to require much exertion. Psychologically demanding work, however, may reasonably require more concentration, greater involvement or be more interesting, and thus is logically related to more hours of work. The lower the psychological demand, the less challenging or interesting it is to pursue, and perhaps this leads to less time working.

Of the eight *a priori* variables entered into the first step of the model building process, only two remained in the final model: social support from family and physical demand of the work. Age, gender, functional status, pain, skill discretion and decision authority were not significant predictors in the final multivariable model. Functional status and pain seem to be natural predictors of hours of work, because it would be reasonable to work less in the presence of physical impairment or pain. However, this was not the case among the respondents in the present study. Functional status was not associated with unpaid work hours in either univariate or multivariable analyses. The majority of respondents had HAQ scores less than 1, and they were more able than samples in most other studies. Perhaps functional status is a predictor only for people experiencing greater functional limitations than the current sample. Both Allaire and Goodenow identified lower functional status as a predictor of limitations in performance of household work (Allaire et al., 1991; Goodenow et al., 1990).

Pain, however, was associated with unpaid work hours in the univariate regression and the initial multiple regression with eight *a priori* variables, but it was excluded from the final multivariable model when other candidate variables were considered. Therefore, when considered in isolation, or with a certain set of variables, more pain is associated with less unpaid work, and this finding is consistent with previous studies suggesting that more pain is

associated with work disability (Allaire et al., 1996; Callahan et al., 1992; De Roos & Callahan, 1999; Wolfe & Hawley, 1998). But, when pain is considered along with other potential predictors, as in the final model of the present study, the strength of the association decreases. Two other prior studies did not find pain to be significantly associated with work disability (Fex et al., 1998; Reisine et al., 1995). This apparent inconsistency suggests that the relative importance of pain as a predictor of work capacity is mediated by other factors.

Because of the strong association between children in the home and unpaid work, and because 70 participants did not have children under 18 living at home, the analysis was repeated with the "childless" group. There may have been important factors associated with unpaid work for these participants that were pushed out of the model by the number of children variable. For this group, family social support remained a significant factor, as did physical demand of the work. But educational level and psychological demand of the work did not remain significant. Instead, two new variables entered the model. Less decision authority and longer disease duration were both associated with more hours of unpaid work.

The issue of decision authority and unpaid work was already discussed to some extent in the preceding section on patterns of work. In this analysis (predicting unpaid hours among childless respondents), it appeared that people who find they have less autonomy in deciding what to do and when to do it tended to be involved in more hours of work. This suggests that those feeling an obligation to work, rather than the freedom to decide if and when work needs to be done, engage in more work. Less decision authority has been associated with cessation of paid employment in previous studies, which implied it may be associated with fewer hours of work, but this was not the case in the present sample.

Longer disease duration, though, appeared as a predictor of unpaid work for the first time. It has been associated with work disability (Allaire et al., 1996; Callahan et al., 1992; De Roos & Callahan, 1999; Doeglas et al., 1995; Mau et al., 1996; Yelin et al., 1980), but not with more work. One of the potential limitations of using time spent working as the outcome measure was the possibility that people with arthritis would take longer to do some tasks. Perhaps this is one such illustration: those with longer duration of the disease may have

accumulated more limitations or adopted a slower pace of work in order to accommodate their arthritis symptoms. This subsequently led to more time in unpaid work. Because there is usually no time limit imposed on unpaid work, it is possible to spend as much time as necessary to get the job done. Women with more severe RA in a previous study of homemakers did not differ from women with mild RA or controls in time spent on household work, but they did report doing a lower proportion of the household work in their home (Allaire et al., 1991). This supports the idea that some people with RA adopt a slower pace of work, and indicates that hours of work alone is not sufficient for measuring productive work.

### 5.5 Factors Associated with Participation in Paid Work

Among the person characteristics studied, gender, perceived pain, social function and occupational balance were significantly associated with paid work hours in both univariate and multiple regression analyses. Men were more likely to be engaged in paid work, and less pain, higher social function and lower occupational balance were associated with more hours of work. In univariate analyses, younger age, better functional status, and higher self efficacy with regard to functional abilities were also associated with more hours of paid work, but these factors did not enter the final predictive model.

The association between men and more hours of work is likely a reflection of societal norms. It is a generalization that does not apply to all individuals, but men are more likely to be full-time employees and women are more likely to take advantage of part-time employment opportunities in order to juggle home and work responsibilities. The association between less pain and more hours of work may be an indicator of the impact of RA on paid work. More pain was a predictor of work disability in previous studies (Allaire et al., 1996; Callahan et al., 1992; Wolfe & Hawley, 1998), and it was anticipated that it would also predict of hours of paid work. In a recent qualitative study of adaptations made by employed adults with RA in order to continue working, Mancuso and colleagues found that pain was one of the main threats and taking additional anti-rheumatic drugs one of the adaptive

strategies to minimize pain (Mancuso, Paget & Charlson, 2000). The finding in the present study that less pain was associated with more paid work hours may reflect more effective medication regimes among a subset of participants.

Higher social function was another person characteristic associated with more hours of paid work. This makes sense because paid work is often conducted in a social setting. People with good social skills who value contact outside the home might be more likely to continue working or seek more work than those possessing a less social nature. One of the moms who participated in the consultation process for this study noted that paid work was important because it afforded the opportunity to interact with adults. It may also be possible that more severe disease has a negative impact on both social function and work participation, thus creating this association. Social function has not been examined in prior studies, so this was a new finding.

Another new finding was the association between occupational balance and paid work. As people reported less satisfaction with the relative time spent in various occupations (paid work, unpaid work, self care, leisure and rest), hours of paid work increased. This association was not reported in prior studies of arthritis and work, but it is an intuitive finding. The obligatory hours spent in paid employment probably limit the amount of time people have for unpaid work, self care, leisure and rest. Although the association was significant, and occupational balance was therefore identified as a predictor, it seems more likely that paid work hours predict occupational balance rather than the reverse. However, occupational balance is likely an issue for those without RA as well, and the lack of a control group in the present study prevents a thorough interpretation of the links between work, RA and occupational balance.

No environment characteristics were associated with paid work hours. This contrasts with the finding of Allaire and colleagues (1996), who noted that more co-worker support was significantly associated with remaining employed. Others found that less social support was associated with work disability in one cross-sectional study of women only, but was not

significant in a second, longitudinal study including men and women (Reisine et al., 1989; 1995). Different measures were used in each study, and conflicting findings may be due to measurement tools rather than the construct of social support. It is difficult to draw any conclusions about the role of social support, from co-workers, supervisors, family, or friends on participation in paid work. The present study focused predominantly on the social environment; it is very possible that other environmental characteristics, especially the physical workplace, may be associated with paid work hours.

Occupation characteristics associated with paid work included psychological demand and managerial job type. Greater psychological demand was associated with more hours. This was also a factor in unpaid work, and some of the same interpretations may apply here. If the work is challenging or demanding, it may require more concentration, or be more interesting, leading to more time spent doing it. Managers were more likely to work more hours than the reference category of service workers. The other two categories, professionals and trades, were not significantly associated with paid work hours. Managerial jobs are less likely to have scheduled hours, and probably demand more hours of work when problems arise or deadlines must be met. In contrast, service workers may have a more regular schedule of work hours, or even fewer hours, since service workers often include job types that take advantage of part-time workers instead of incurring the costs associated with fulltime contracts (sales positions, for example). One may have expected the professional job type to also be associated with more paid work hours, for reasons similar to managerial jobs. In prior arthritis work disability studies, non-managerial/non-professional job type was associated with work disability (Allaire et al., 1996; Callahan et al., 1992; Yelin et al., 1980; Yelin, 1995). That is, service workers and trades workers were more likely to stop work prematurely. In the present study, these service-type jobs were associated with fewer hours of work, but it is not known if they are working less because of their job type, or because of the combination of their arthritis symptoms and job type.

The prediction of paid work hours may have been limited by the nature of paid work itself. There is a natural "ceiling effect" on paid work hours provided by work schedules or contracts that dictate a full-time week of 35 or 40 hours for some employees. Others,

working part-time, may have chosen to do so for reasons other than their arthritis. Thus, the association observed between predictor variables and work hours may have been underestimated.

#### 5.6 Work Limitations Secondary to RA

Most of the differences between participants limited by their RA and those not limited were related to disease status and health status variables. The "work limited" group reported more active disease, more pain, and more fatigue, so it follows that they would also find themselves limited in the amount of work they can do. The group with work limitations reported lower health status on all of the SF-36 subscales except the two assessing mental and emotional health. When SF-36 scores are standardized (0-100 scale for all measures, with 100 representing the desired health state), it helps to interpret the magnitude of the differences. Not surprisingly, the largest difference is in role limitations resulting from physical health, a difference of 28%. The group reporting work limitation had a standardized mean score of 27 compared to 55 for the not limited group. This illustrates that both groups had role limitations compared to the general population (Ware et al., 1993), and that the "work limited" group had substantial role limitations as a result of their physical health status. [The median standardized score for physical role limitations for the general population is 100, and the 25th percentile is 50 (Ware et al., 1993)].

It is interesting that the two groups did not differ on the emotional and mental health subscales. Although arthritis is a physical condition with physical impairments, it would not be unusual for physical limitations to take an emotional toll. If occupation is a determinant of health, then those who are limited in pursuing valued occupations might find that their emotional health is affected – it can be frustrating when one cannot work as much as one would like, assuming that one likes the work. However, in this sample, there was no association between work limitation and mental or emotional health. In terms of hours worked, the work limitation was actually in paid, not unpaid, hours. Perhaps their

engagement in unpaid work was sufficient to maintain a sense of productivity and not adversely influence emotional health. The lack of association between work limitations and emotional or mental health status was in contrast to prior studies. MacKinnon (1992) found that working less than 35 hours per week was associated with psychological distress in both people with RA and healthy controls. Goodenow and colleagues (1990) reported that functional limitations were associated with both household role limitations and depression among women with RA. The instruments used to measure emotional and mental health in the three studies differed, which offers one explanation for disparate results. The relationships among participation in work, physical capacity to work, and emotional health warrant further study in order to determine under what conditions they are (or are not) associated.

In the multivariable analyses, the first step was to determine the contribution of eight *a priori* variables in predicting work limitation. These were age, gender, functional status, pain, co-worker support, job physical demand, skill discretion, and decision authority. Six factors had been significant predictors in several prior studies (age, functional status, pain, physically demanding work, and work autonomy, which was measured in the present study with skill discretion and decision authority, refer to Table 2 for summary of studies). Gender was a significant predictor in only two prior studies (De Roos & Callahan, 1999; Wolfe & Hawley, 1998), and co-worker support had been proposed as an important variable but only specifically studied once (Allaire et al., 1996). When these eight variables were entered into a regression model to predict work limitation, four of them were significant (functional status, pain, skill discretion and decision authority), and four were not. When other candidate variables were considered, skill discretion and decision authority were no longer significant predictors in the "best model."

In the final model, the predictors of work limitation were lower functional status, more pain, work that was less psychologically demanding and being a household worker. People who identified themselves as limited were working only 6 paid hours compared to 23 paid hours among those not limited, and there was no difference in unpaid hours. Lower functional status and more pain were associated with work disability in several studies, so it

was not surprising that these variables also predicted work limitation among paid and unpaid workers. A new finding was the association between decreased psychological demand and work limitation. Psychological demand was not included in the prior work disability studies. Perhaps people who find their work challenging, and thus psychologically demanding, are more likely to continue working and therefore less likely to report work limitations. In the consultations that occurred with people with RA in preparation for the present cross-sectional study, interesting, challenging or enjoyable work were cited as reasons for working. An alternative explanation is that jobs that are less psychologically demanding may, on average, be more physically demanding. However, this was not supported in the present study because the correlation between psychological demand and physical demand was positive.

Being a household worker was almost a surrogate for the outcome work limitation. Respondents who classified themselves as limited appeared to do so because they could not pursue paid work at they level they wished to, and thus, the job type associated with their main form of work was household worker.

Contrary to prior work disability studies, age and physical demand of the work were not significant predictors of work limitation. Respondents whose work was limited by RA were, on average, approximately the same age as those not limited. So, while age was a predictor of work loss in prior studies, it was not associated with self-reported limitations in work hours in the present study. Those not limited in their work reported slightly more physical demand (exertion) associated with their work than did respondents with work limitation (significant at p = .06, see Table 17). In the initial regression model (Table 31) the odds ratio suggested that lower physical demand was associated work limitation, but it did not meet the criterion for remaining in the model. Although not statistically significant, the result appeared consistent with previous findings that a mis-match between physical demands of the work and physical capacity of the individual lead to work disability.

#### 5.7 Satisfaction with Work Performance

Satisfaction with work performance was proposed as a possible outcome variable by people with arthritis in the consultation process. They suggested that the impact of arthritis on work went beyond changes in hours worked, and influenced how satisfied they were with their work performance regardless of how many hours they engaged in work. Measuring hours of paid and unpaid work would not capture some of the impact. Therefore, participants were asked to rate how satisfied they were with their ability to perform their main work activity. The largest contributors to predicting work satisfaction were self efficacy in managing arthritis symptoms and self efficacy with regard to function. This was an exploratory analysis, but the strong presence of self efficacy variables suggests that programs such as the Arthritis Self Management Program (Lorig & Holman, 1993) which emphasize efficacy-enhancing strategies first, before moving on to other patient education topics, are on the right track. Programs related to work retention and return to work might also benefit from the inclusion of efficacy-enhancing strategies in order to improve satisfaction with work performance.

Greater work satisfaction was also associated with more skill discretion of the work and smaller household size. The association with more skill discretion seems intuitively appropriate: if the work affords opportunity to use one's skills appropriately and at will, then one will be more satisfied with overall work performance. The association with smaller household size could be a spurious finding. However, more children (and thus larger household size) were associated with more hours of unpaid work, and it has already been hypothesized that children create more work. Maybe it is easier to be satisfied with work performance if there is less working waiting to be done. Because household size is not a readily modifiable characteristic, speculation on why it is associated with work satisfaction may not be as important as further study of modifiable factors, like self efficacy.

# 5.8 Gender Differences

Gender differences could not be fully explored because of the few number of men participating. Among the potential predictor variables, men and women differed on five: general health status, vitality, self efficacy pain, commuting difficulty, and social support from friends. None of these variables entered the multivariable analyses predicting paid or unpaid work hours, work limitation, or work satisfaction. However, issues around pain and pain management might be worth further exploration. In the final regression model predicting paid hours, both gender and pain were contributing factors. When the analysis was repeated for women only, pain was no longer a significant predictor. Do women cope with pain better when it comes to paid work? Among the participants in this study, women reported slightly less pain than men (SF-36 bodily pain subscale), but it was not significantly different. However, women reported significantly greater self efficacy with regard to managing pain (a difference of 8%, p = .04). So perhaps women do manage pain more effectively than men. The differences were small, and may not be reproducible in other samples. De Roos and Callahan (1999), in a large cross-sectional study, found that women reported more pain than men, and were more likely to be work disabled.

#### 5.9 Strengths and Significance of the Study

This study describes the current situation with regard to factors associated with level of participation in paid and unpaid work among a sample of adults with RA from British Columbia. It adds to only two other Canadian studies investigating work and arthritis, MacKinnon's examination of occupational profiles (MacKinnon, 1992; MacKinnon et al., 1994) and Lacaille and colleagues' (1999) work disability study. It expands upon MacKinnon's work by examining some of the person, environment, and occupation factors associated with paid and unpaid work, and it expands upon Lacaille's work by examining unpaid work among adults with RA. The study adds to the sparse literature on the effect of RA on unpaid work, which has been given little attention in prior research, in any country.

The consultation with people with RA in designing the survey was unique compared to prior studies. They helped identify the most important potential predictors to study, and proposed the two secondary outcome measures. This consultation is consistent with the client-centred philosophy (CAOT, 1997) endorsed by many health agencies, and may offer more confidence that the findings are relevant to people with arthritis and their health care providers.

The study identified several factors for consideration in intervention programs aimed at helping people with arthritis maintain or return to productive work, whether it be paid or unpaid. The intended emphasis was on the identification of modifiable factors, without ignoring the influence of non-modifiable factors. The use of the PEO model helped organize the selection of factors for study, and provided a framework that acknowledges the complexity of the relationships among factors related to participation in paid and unpaid work. By identifying associations among person, environment and occupation factors and participation in paid and unpaid work, the study helped set priorities for interventions and created hypotheses for intervention studies. While it is not possible to change the number of children in a household, it is possible to improve functional capacity, enhance self efficacy, manage pain, and modify task demands. For example, it could be hypothesized that a combination of exercise (to improve physical capacity) and efficacy-enhancing strategies (to mediate pain and increase confidence in functional ability) in a supportive group setting will reduce work limitations, improve work satisfaction and participation in paid and unpaid work. Or, it could be hypothesized that involving family in educational programs, and use of adaptive strategies to better match the psychological and physical demands of the work to the individual's work capacity, will increase participation in paid and unpaid work.

This study has implications for both clinical programs and future research related to work and arthritis. Factors such as pain, functional status, type of work and physical work demands were expected to be associated with participation (or limitations) in work based on previous research findings. The present study added several new variables for consideration: social function, social support, psychological work demands, self efficacy, and perceived occupational balance. These factors require confirmation in future research, but offer some

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interesting insights into unraveling the complex associations among factors influencing participation in paid and unpaid work. Although paid and unpaid work are both productive occupations, the study demonstrated several differences between paid and unpaid workers. In terms of predicting hours of work, only one factor was associated with both paid and unpaid work, and that was psychological demand of the work. Work retention/work rehabilitation programs may need to consider different approaches for clients based on their primary form of work.

The factors (summarized in Table 38) could serve as an initial framework for developing a taxonomy of person, environment, and occupation factors associated with participation in paid and unpaid work. This list may inform assessment approaches used by occupational therapists, social workers, vocational rehabilitation counselors, physicians, and others, to work with clients in identifying current or potential problems associated with paid and unpaid work. The factors should also be considered as important additions to existing rehabilitation programs aimed at preserving function, especially related to work retention. Because the factors significantly associated with work participation and work satisfaction are in physical, psychological and social domains of practice, multi-disciplinary approaches to intervention will be necessary. The framework can also serve as a starting point for future research, in order to verify the contributions of these factors and add other factors as they are identified. And finally, it may stimulate thinking among health care providers working with people who have other chronic illnesses or injuries that threaten participation in paid and unpaid work to consider similar factors in their assessment, intervention and research.

As this study was nearing completion, a qualitative study of 22 working adults with RA was published (Mancuso et al., 2000). It was conducted to explore the circumstances of people with RA who maintained employment. As was demonstrated in the literature review for the present study, a fair amount of attention has been given to identifying risk factors associated with stopping paid employment; Mancuso and colleagues wanted to explore characteristics of people who continued working. They used structured interviews to collect their data, and this approach helped to identify several challenges or threats to maintaining employment and the adaptive strategies used to respond to those challenges. Among the

findings was the important impact of psychological stresses, and one of these was balancing work, family and personal roles. This lends some support to the present study's identification of occupational balance as an important factor related to work participation. Neither study could identify the direction of association because of methodological limitations. However, the construct of occupational balance should be studied further because it is a perception, and perceptions can be modified. If perceived occupational balance can be improved, perhaps work participation and work satisfaction will also improve.

One of the adaptive strategies proposed by the informants in Mancuso and colleagues' study was to "modify your home life" in order to maintain employment. In addition to speaking to the issue of occupational balance, this suggests that paid and unpaid work should be studied together rather than segregated. Other than MacKinnon's examination of occupational profiles, all other RA work studies focused exclusively on paid or unpaid work. The present study demonstrated that it is possible to examine paid and unpaid work concurrently, and may also suggest ways to improve future studies. For example, the measurement of occupation characteristics was limited to the main form of work for most respondents in this study. It may have been useful to encourage all respondents to rate both their paid and unpaid work characteristics. Better still, the relationship between paid and unpaid work should be explored in more detail, especially among people who report dissatisfaction with occupational balance.

# 5.10 Limitations

There are limitations inherent in cross-sectional designs. They provide only weak evidence of causal associations because of the uncertainty of the temporal relationship between "predictors" and "outcomes." The interpretation of results has been cautious in that respect, acknowledging that associations do not infer cause and effect. Additionally, multiple comparisons increase the chance of identifying spurious associations. The modelbuilding approach used, intended to manage collinearity among variables, also helped minimize the number of comparisons considered at one time. Associations that are

consistent across several studies will identify factors with true relationships to paid and unpaid work.

The study may be limited by a selection bias. Perhaps only those who were actively engaged in paid and unpaid work responded to the invitation to participate, a kind of "healthy worker effect" where the sample contains an over-representation of healthy workers (Checkoway, Pearce, & Crawford-Brown, 1989). Overall, 40% of those invited to participate did so, and the return rate for surveys was 89%. Participants did not differ in terms of age or disease duration compared to a sub-group of 30 non-responders, and their personal characteristics were compared to those of other study samples when considering how to interpret the findings. It has already been noted that they were a relatively "able" group, and this limits the generalizability of findings to similarly-able adults with RA. Because they were identified through the community-based practices of several rheumatologists, they may be different from typical patients in a general practice or from those attending a highly specialized clinic.

Information bias is another potential limitation to cross-sectional designs, and refers to over- or under-reporting symptoms or behaviours (Checkoway et al., 1989). In the present study, information from various self-reports was cross-referenced. For example, the Occupational Questionnaire diary was used to validate individual's estimates of paid and unpaid work hours last week; and functional status was compared across two different measures (the HAQ and the SF-36 physical function subscale). The consistency between measures suggested that information bias was not apparent. Information bias can also be minimized through the use of close-ended questions, so that responses are not left open to interpretation by the investigator (Hennekens & Buring, 1987). The survey used in this study relied on close-ended questions, and the predictor variables were based on previously validated instruments.

The analysis of paid work hours was limited to respondents who reported on the work characteristics of paid work, so it excluded respondents who were no longer working (or who considered their unpaid work to be their main work). Therefore, people with more severe

disease or those who left paid work because it was too demanding may have been excluded, which could result in underestimating the effect of some factors on hours of paid work.

The lack of a comparison group means that it is difficult to identify which associations are specific to people with RA and which associations are true regardless of disease status. In fact, the study demonstrated that there is a complex web of associations among person, environment and occupation characteristics that influence work participation. The cross-sectional survey did not permit full exploration of these issues. Nor was it feasible to explore all of the potential variables influencing paid and unpaid work. A broader study of factors would be possible using a qualitative approach, one in which a finite number of closeended questions did not limit the identification of potentially important factors. Further, the interactions among factors probably vary depending on the circumstances, and this could be more appropriately investigated using in-depth interviews or similar methods to explore different individuals' work experiences. Involving people with and without RA would help to tease out associations inherent in the person-environment-occupation relationship and those specific to RA. Such studies would help refine the conceptual model.

#### 5.11 Summary and Conclusion

The purpose of the study was to investigate factors associated with participation in paid and unpaid work, and there were four main objectives. Each objective was achieved. The first was to consult with people who have RA, health care providers and academics to ask what aspects of paid and unpaid work were important to study. The consultants provided several suggestions that informed the main study. The second objective was to develop a measure of participation in paid and unpaid work. Based on the consultations and some of the difficulties in defining measurable concepts related to paid and unpaid work, hours of work was selected as the main outcome measure. Because Statistics Canada had conducted time use studies, it was advantageous to adapt their questions and categories of paid and unpaid work in order to make some comparisons with the general population. Satisfaction

with work performance and work limitations due to RA were secondary outcome measures selected for study.

The third objective was to design and field-test the mail survey. The pre-test and field test proved valuable in ensuring that the survey was feasible. The field test demonstrated that the measures of paid and unpaid work, work limitation and work satisfaction were reliable and valid. The final objective addressed the main purpose of the study, to conduct a cross-sectional survey to identify factors associated with participation in paid and unpaid work among adults with RA.

Participants in the study were engaged in both paid and unpaid work, but overall worked less than the general population. The difference was approximately equivalent to one day of work, suggesting that RA does have an impact on work participation. Factors associated with more hours of unpaid work were more children in the household, more social support from family members, being a post-secondary graduate, and more physically and psychologically demanding work. Factors associated with more hours of paid work were gender (being male), less pain, higher social function, greater psychological demand of the work, lower occupational balance and being in a managerial job. About one-third of the participants in this study were limited in their work by RA, and factors associated with work limitation were lower functional status, more pain, being a household worker, and less psychologically demanding work. In general, study participants tended to be satisfied with their ability to perform their main work activity. Factors associated with greater work satisfaction were higher self efficacy, greater occupational balance, more skill discretion at work, and smaller household size.

Some of the factors associated with paid and unpaid work may not be unique to people with RA, but may represent relationships that affect work participation in general. For example, perhaps all working age adults with more psychologically demanding work engage in more hours of paid work because it is interesting, challenging, and by nature represents a job that is not confined to a "9 to 5" work schedule. Certainly, children in the household will increase the demand for unpaid work regardless of the presence of RA in the

parent or caregiver. It would be useful to obtain a comparison sample to assess the extent to which RA has an impact on hours of work above and beyond the associations that may result from environmental or work demands for all workers in similar situations.

The major reason for conducting the study was to identify factors associated with participation in work, in order that these factors be considered in rehabilitation and education programs aimed at helping people with arthritis maintain or return to work. Some of the factors associated with paid and unpaid work cannot be modified, for example, number of children. However, several suggestions can be made. Self efficacy, pain management, and social skills are all potential topics for inclusion in rehabilitation programs. Physical conditioning programs to maintain functional status may be important in reducing work limitation. Programs involving family members may be one way to improve social support. Ergonomic programs, usually related to adapting work place physical environments to match physical capacity of workers, might be expanded to better address the psychological interface, as well as moving into unpaid work places. Because the factors associated with work participation in this study represent physical, psychological and social domains, a multi-disciplinary approach to intervention is recommended. The relationships among person, environment, and occupation factors are complex, and this study provides one snapshot of their influence on participation in paid and unpaid work.

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# Appendices

- 1. Consent Form for Group Discussion/Interview Participants
- 2. Notes From Discussion Groups and Interviews
- 3. Initial List of Potential Variables for Study
- 4. Cover Letter and Pre-test Questionnaire Packet
- 5. Cover Letter for Field Test
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- 11. Cases that Reported  $\geq$  70 Hours of Work Last Week

# THE UNIVERSITY OF BRITISH COLUMBIA

#### **APPENDIX 1**



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Tel: (604) 822-7392 Fax: (604) 822-7624 Website: http://www.rehab.ubc.ca/srs.html

# Participation in Paid and Unpaid Work by Adults with Rheumatoid Arthritis

Principal Investigator: Catherine Backman, Senior Instructor, School of Rehabilitation Sciences and PhD Student, Department of Health Care & Epidemiology Telephone: 822-7409 E-mail: backman@rehab.ubc.ca

<u>Co-Investigator</u>:

Dr. Andrew Chalmers, Associate Professor, Faculty of Medicine Telephone: 875-4111, ext. 62426

### **Purpose of the Project**

The overall goal of this project is to identify factors associated with participation in productive work activities by people with rheumatoid arthritis. Ultimately, this information will be useful in the design of rehabilitation and education programs aimed at helping people with arthritis maintain or improve their ability to engage in both paid and unpaid work.

#### Procedures

A first step in achieving the overall project goal is to determine how to measure productivity. This will be done by asking people with arthritis and health care providers to identify important characteristics about the work they do (employment and around the house, volunteering or in school). Participants are invited to offer suggestions about the best way to measure productive work in small group discussions lasting 60 to 90 minutes. People interested in participating but unable to attend a group session will be interviewed by the principal investigator.

Suggestions will be used to formulate a questionnaire for the second phase of the study. After the group discussion or interview, you will be asked if you are willing to read, critique and respond to the first draft of the questionnaire. If you agree, you will be asked to provide an address to which the questionnaire can be mailed. The draft questionnaire will take up to an hour to complete. A stamped return envelope will be provided. By completing and returning the questionnaire it will be assumed that you have given consent to participate in that activity.

### Confidentiality

Suggestions arising from group discussions and interviews will be collected in such a way that no one will be able to identify which are yours. If you choose to complete the draft questionnaire, you are asked not to put your name on the form. In this way, all of the data collected remain anonymous. Only combined data from the entire group of participants is maintained for analysis and research publication.

All information collected as part of this study will be kept in a locked filing cabinet or on a computer accessible only by password. Only the principal investigator and a research assistant collating the data will have access to the files.

### Compensation

No financial compensation is offered for your participation. In order to facilitate your participation in a group discussion, your transportation costs will be reimbursed upon presentation of a parking receipt, taxi receipt or bus transfer.

#### Contact

If you have questions about this study, you may ask the investigator now, or later by telephone. Call Catherine Backman at 822-7409, or Dr. Andrew Chalmers at 875-4111, ext. 62426.

If you have any concerns about your rights as a research subject, you may contact Dr. Richard Spratley, Director of Research Services at the University of British Columbia at 822-8598.

#### Consent

You are not obligated to participate in the discussion group, interview or to complete the questionnaire. You have the right to refuse to participate or to omit individual questions. Refusal will not jeopardize your medical care or treatment.

By signing this consent form you agree to participate in a discussion group or interview.

A copy of this form is provided to you for your records.

Signature	Date
Witness Signature	Date

page 2 of 2

### Appendix 2

## Notes From Discussion Groups and Interviews

What Aspects of Paid and Unpaid Work are Important to Study?

- need to define work (sometimes it includes housework or volunteer work, sometimes it doesn't)
- not everyone will think of unpaid work the same way
- flexibility of work is important
- maybe separate paid and unpaid work, put questions in different categories
- type of work is important: if I enjoy it I'll work more, if not, I'm more fatigued, less likely to work
- when I love my work (gardening) I do things I shouldn't do (work too long, don't rest my joints) because I'm happy, inspired
- finding something productive or to enjoy is important to everybody, disabled or not
- there's more pain if you dislike the work
- ask why do you work? it's probably related to necessity and to view of one's self and roles in life
- work does not match the ability of my body
- satisfaction with work is important; even though I had to give up paid work (couldn't do it fast enough to be employed) I still want to do it in my own time to my own satisfaction
- I haven't lost skills, just can't keep up with a production schedule
- it's heartbreaking that society assumes I lost my mind when I lost control of my limbs
- perception of ability to work probably doesn't match who actually works function and working might not be related
- physical demands of work, RA can be invisible and you can be harassed if not keeping up with work
- I spend a lot of time worrying about work
- what kind of a toll does working take (psychologically) it's important to stay in the "well" camp (with others who don't have RA), what kind of a toll does this masquerade take?
- downsizing and other factors at workplaces result in cutting jobs, I felt forced into sharing personal information about my health/RA
- accommodations at work, some employers are very accommodating
- availability of 'return to work' programs, but some people probably neglect to use them in order to be "normal"
- work is very social, making friends is important to work
- sense of control, ability to manage symptoms, being able to work at my own pace or take time off without demeaning myself
- supervisor confidentiality
- is it physically demanding, what are your responsibilities?
- at the end of the day, do you get the job done?
- fatigue, discomfort at work

- even computer work is hard, filing too, just sitting is difficult
- sometimes you just can't do it
- have a standard list of activities, basic responsibilities, plus a list that people fill in with activities specific to them, leave lots of blank space, room to write
- physical work, the amount of physical work required is important
- degree of physical and mental stress is important
- stress causes more pain
- physical demands of the job and physical capacity of the individual sometimes don't match, but I'm not a total "cripple"
- I need options, some things I can and can't do, I need to make decisions or choices about my work
- need to be free to avoid getting into situations that cause pain
- spacing and pacing, doing just one thing each day
- takes twice as long to do housework, therefore you're less productive and this is a limitation to working
- working with your hands is hard
- problems with deadlines, need work to be flexible
- fatigue, mental state, physical capacity, even the weather affects work
- autonomy, flexibility, is important in the workplace
- what would you like to spend your life doing? to feel productive? to make life worth living?
- housework is work, but if you're in pain, you change your standards
- parenting is important, but I don't think it's work, need to define work
- emotional health is important, have to feel able to cope with competing demands, different roles, need to be balanced

### How Should Paid and Unpaid Work be Measured?

- time is a big factor
- mental anguish is part of the equation (how satisfied you are with the work you get done) but it's hard to measure
- quality of work, whether it leads to recovery, is self-supporting
- there is a monetary value to all work, could estimate that
- better to ask 'what makes you feel productive, satisfies your interests?' not ask about paid work, because it may be done just to pass time and make money
- ask 'are you presently working? yes or no' and 'what did you do before RA?'
- don't ask what proportion of time you spend working (or doing or feeling anything) it's too hard to figure out proportions
- how many hours you spent working is ok, sometimes difficult to answer
- can you do this (work), on a typical day, or in a typical week for you need to be specific about time frame (this week, today, last month, nothing too far away)
- time is an important factor, but it's not the only way to measure productivity, try to think of something else
- must measure own perspective, own perception, including changes that RA causes to work

- quality, or how well activities are done would be useful information, too
- work diary or journal is a good idea, but too time-consuming
- I tried a journal, it requires discipline
- proportion of time spent working before RA and now would be good to know but it's too hard to measure, to remember
- don't go with percentages, they're too hard
- can ask what activities are too hard to do now, slower, can't be done because of RA
- okay to ask about an average or typical day, it seems valid, and it would be easy to answer
- there are ups and downs (flares), but also average days
- maybe ask whether or not you're satisfied with the work you get done in a day, with what you accomplish
- diary is not a bad idea, if it's simple to fill out
- could do a regular day versus a medication day I'm wiped out the day I take my methotrexate
- independence in work, for example, do you need assistance to lift or carry or change a light bulb, take care of the house
- interviews are better than surveys, there's too much to say
- time spent working is good, but it's not the only thing what if RA makes you work less, or differently?
- ask "do you work less now than before your RA?"
- I do way less housework because of my RA, your standards change when you have pain, or are tired; I'd rather spend my time with my family
- need to know not only what work people do, but whether or not they value it, are interested in it, or can take it or leave it
- the kind of work is important, if it's physical eventually your arthritis will keep you from doing it
- if the work is interesting, you'll probably find a way to do it

Are There Other Factors that Influence Your Ability to Work?

- need more counselors, there's lots to talk through, need time to work through the issues related to working
- equipment that makes doing the job easier
- stairs, environmental barriers location of work is a barrier, don't want to indicate that I'm disabled from the outset but need to find out if there's stairs, 9 times out of 10 the accounting department is up stairs
- having ergonomic work stations, or someone at work to help set things up properly, having the right equipment
- the effect on emotions and self esteem
- hardly any employment counselors, or skilled ones anyway, you really need good advice
- transportation is a big problem, can't make it to the bus stop or can't make it up the bus steps, can be very restrictive
- Handidart is very restrictive

- weather conditions, hard to walk on ice
- sleep will affect feelings and ability at work
- transportation is not an issue, childcare is a big issue, need to make plans
- household responsibilities, financial issues cause stress
- to feel productive I need to work outside the home, be with adults
- need to explore options, I'd like to stay in nursing abut no shift work, less physical stress, the emotional stress is ok, I can handle that
- stage of arthritis is important, if I have a flare the whole day is shot
- there's no in-between when people ask about work, you're either able or disabled
- RA even limits volunteer work, no acknowledgment if you're not able to do it on a regular basis
- need retraining options
- changing jobs may jeopardize pension
- main reason to work or not is money
- if we can convince insurance companies, pension plans to give the opportunity to work part time, or go back to work without jeopardizing the pension, that would be good
- even doing volunteer work threatens disability payments or Canada pension, as soon as you try they cut off benefits
- really important to have a rehab centre, much easier to deal with all the services and resources during an in-patient stay, need a break from routines (both paid and unpaid work), concentrate on improving health, then go back to work
- re-training is really important, I'm really interested in acquiring new skills, barely making ends meet now, but I can't go to work and go to night school, too tired
- need to re-train while still healthy, before RA gets too bad
- can't cope with burdening other people, so I take more time off, and they give my work to others
- volunteer work is my job when I'm unable to work
- need to contribute to society, do it for myself, need to work
- support system, my husband, family, is really important
- work atmosphere is important, it's tough for everybody if the work is driven by fiscal restraint
- the whole disability pension business, no one is trying to rook the system, it's not enough to live on, so no one would go on CPP unless necessary, should be able to work a little to supplement that income
- family, friends, employer support is important
- there's a stigma attached to people not working full-time, that's the thing about North America, doesn't happen in other countries. Everyone has to fit in a slot, if they don't, no one knows what to do with them.
- salary reduction is very difficult
- we all have financial obligations, I've always had to work, I'm single so I need to support myself. Working full time is detrimental to my RA, but I have to work to meet expenses.
- medications, heavy drugs just knock me out

- time of day is an important theme, can't always be productive some times of day, or get everything done in a day
- whether or not you're in remission, duration of disease
- the pain or fatigue that you have
- sense of control over RA
- all kinds of health issues, physical, mental, whether or not you have other health problems
- support from people at work, colleagues, supervisor
- need to ask about what you can do, not just what you can't
- do you have enough support? I have a lot of support from friends, family, and it makes a difference. You can do more outside work if your family helps with housework.

### Comments About Questionnaires

- different people are filling them out, keep them simple as possible
- big type (font), 14 points at least
- simple responses, like yes, no, maybe, sometimes, never
- yes, no responses; if the answer's yes, then ask more questions
- not very many pages, not too long
- shorter is always better, if it only takes a few minutes you're more inclined to help out and do it
- number of pages depends, after a few you can tell how easy or difficult it's going to be if it just takes seconds a page, doesn't matter how many pages
- it's hard to write a lot, just check boxes or circle items, and short answers is good
- lots of white space, don't make it too crowded
- not small writing, and not small spaces to write in, not those teeny tiny boxes to check off

#### Comments From Health Professionals/Scholars

- work is a big question, lots out there to study
- employment is just one aspect, people feel productive for different reasons
- different ways to measure productivity benchmarks in different industries, whether or not quotas are reached, cost per unit of product, etc.
- time spent working is one aspect, but many people with RA take longer to get the job done
- they are challenging questions (how to measure participation in paid and unpaid work), unpaid work really needs more attention
- the basic notion of using opportunity cost is ok and standard for economists I've always thought is somewhat unrealistic, since unpaid work probably involves lower levels of supervision than paid work. My wife gets bored making dinner for instance, so she has a phone with a very long cord and chats while she is in the kitchen. On the job she is very focused and puts in long hours without even a break some days. The motivation for unpaid work may be important too.
- people with non-economic motives may have different patterns of work, not just less intense, than paid workers

- the measurement of productivity is based on economic principles and is quite complex – probably want to stay away from that perspective government agencies like Statistics Canada have adopted various ways of measuring labour force participation; they may use some economic principles but these are probably old
- I'm sure a much simpler approach can be used, whether or not people are working or not, doing what they want to do
- market value of the work is just one way to look at valuing work, but I don't think that's what you want to get at you don't want to assign a value to people's work based on how well they're paid
- people come for help when they can't do the work that is important to them, when they have physical or other limitations to getting the job done; we try to find ways to match their functional status and the demands of the work, adapt one or the other
- one part of being work disabled is needing to change work, but going part-time isn't always a work disability
- self employment is a big concern, if you can decide when and how you work, you're able to work more
- hours of work is ok, but a bit limiting it doesn't account for increased difficulty or slower pace associated with arthritis
- people usually say they feel productive when they're satisfied with their work, not always by how much they work how much they work might have a financial implication, though
- the cost of hiring household help might be one way to get at some of this if you need a homemaker, or you hire a cleaning service because you can't do the work, or you choose to give this part of your work away, it might tell you something
- when it comes down to it, some people don't want to work and others do; you really have to go on their goals, what makes them satisfied, and help them to do that if they aren't satisfied with their work, then you want to offer interventions that improve their satisfaction with work
- I don't know of any measures for work, other than measure work capacity. Starting with how much people are working is probably as good as any. I don't think there's that much information out there, we have to start somewhere.
- Patients tell us they work less, but I don't think there's any evidence about how much people with RA work, especially unpaid work. Lots of them take disability pensions, so it's a problem, but for those still working, what makes the difference?
- relative time spent in work compared to other activities is important if a third of the day is taken up doing basic activities of daily living or taking care of health issues, it will cut into productive and leisure time, it disrupts the balance
- people value different roles, probably affects their time spent working

## Appendix 3 Initial List of Variables Considered for Study

- hours of work (total, paid, unpaid)
- kinds of work (create categories of paid, unpaid work)
- importance of work
- satisfaction with work
- satisfaction with day's achievements
- work habits before and after onset of RA or,
- work limitation resulting from RA
- general well-being
- physical, mental, emotional health
- functional status
- disease status (disease duration, severity)
- symptoms: pain, fatigue
- coping skills or self efficacy
- environmental supports
- social support
- work characteristics: physical demand, autonomy, stress
- commuting, transportation to and from work or to do household errands

.

- pension status
- degree of difficulty with different aspects of work
- balancing different roles, responsibilities

# Participation in Paid and Unpaid Work Draft Survey Questions

In this survey ....

paid work refers to all types of employment, full-time, part-time, self-employment

**unpaid work** refers to productive activities for which you are not paid, including (but not limited to) household work (cleaning, cooking), household maintenance (yardwork, repairs), care-giving (child rearing, elder care), schoolwork, and volunteer work

Together, paid and unpaid work encompass all of your productive work, which is distinct from self care (dressing, bathing, eating) and discretionary time (relaxing, leisure, hobbies and recreation).

In this survey.....

Questions are listed in the left hand column. Respond in the right hand column, by checking  $[\checkmark]$  the bubble after the appropriate answer, or circling the appropriate rating where there is a rating scale, or filling in the blank.

If you were on vacation last week, answer questions 1 through 6 for a typical week when you are not taking a vacation.

1. Last week, did you do any unpaid housework, like cooking, cleaning, grocery shopping, or laundry for your household?	Yes O ➡ For about how many hours? No O
2. Last week, did you do any unpaid	Yes O
work to maintain or improve your	→ For about how many hours?
home, yard, or automobile?	No O
3. Last week, did you provide any child care or caregiving to another member of your household?	Yes O → For about how many hours? No O
4. Last week, did you do any volunteer	Yes O
work for an organization in your	→ For about how many hours?
community?	No O

5.	Last week, did you spend any time going to school and doing schoolwork (studying)?	Yes O → For about how many hours? No O
6.	Last week, did you do any paid work at a job or business?	Yes ○ → For about how many hours? No ○ → In what year were you last employed?
7.	What do you consider to be your main occupation? That is, the paid or unpaid work activity that takes most of your time and energy.	
	Is the above a self-employed position?	Yes O No O
8.	On a scale of 1 to 10, how satisfied are you in your ability to perform your main work activity?	1       2       3       4       5       6       7       8       9       10         very       very       very       very       satisfied       satisfied
9.	How satisfied are you with the balance of time you spend on work, self-care, leisure, and rest?	1         2         3         4         5         6         7         8         9         10           very         very         very         very         satisfied         <
10.	At the end of the day, how satisfied are you that you have accomplished what you had set out to do?	1         2         3         4         5         6         7         8         9         10           very         very         very         very         satisfied         satisfied
11.	Do you work as many hours per week as you would like?	Yes O No O → I work more hours than I want to O → I work less hours than I want to O

<ul><li>12. If you work LESS than you would like, why?</li><li>[Not applicable? Skip to #13.]</li></ul>	because of my arthritis O because of another illness O other personal responsibilities O other household responsibilities O could only find part-time work O another reason O specify:
<ul><li>13. If you work MORE than you would like, why?</li><li>[Not applicable? Skip to #14.]</li></ul>	my type of work requires it O financial reasons O don't want to be considered unable to do the work O part-time hours not available O another reason O specify:
14. Do you need to travel outside your home in order to do your work?	Yes, I regularly commute to work O Yes, I do errands outside the home O No O ➡ Skip #15 - 17, go to #18.
15. How do you travel?	transit O own car O carpool O walk O bicycle O handydart O other O specify:
16. How long does it take, on average, to commute?	hours per day
17. How difficult do you consider your commute?	1       2       3       4       5       6       7       8       9       10         very       not at all       diffcult       difficult

Answer the remaining questions with respect to your main work responsibilities. Write down the main work role you're thinking of here:

18. My work requires that I learn new things,	O strongly disagree	O disagree	O agree	O strongly agree
19. My work involves a lot of repetitive tasks.	O strongly disagree	O disagree	O agree	O strongly agree
20. My work requires me to be creative.	O strongly disagree	O disagree	O agree	O strongly agree
21. My work allows me to make a lot of decicions on my own.	O strongly disagree	O disagree	O agree	O strongly agree
22. My work requires a high level of skill.	O strongly disagree	O disagree	O agree	O strongly agree
23. I have very little freedom to decide how I do my work.	O strongly disagree	O disagree	O agree	O strongly agree
24. I get to do a variety of different things in my work.	O strongly disagree	O disagree	O agree	O strongly agree
25. I have a lot of say about what happens in my work.	O strongly disagree	O disagree	O agree	O strongly agree
26. I have an opportunity to develop my own special abilities.	O strongly disagree	O disagree	O agree	O strongly agree
27. My work requires me to work very fast.	O strongly disagree	O disagree	O agree	O strongly agree

28. My work requires me to work very hard.	O strongly disagree	O disagree	O agree	O strongly agree
29. My work requires a lot of physical effort.	O strongly disagree	O disagree	O agree	O strongly agree
30. I am not asked to do an excessive amount of work.	O strongly disagree	O disagree	O agree	O strongly agree
31. I am often required to move or lift very heavy loads in my work.	O strongly disagree	O disagree	O agree	O strongly agree
32. My work requires rapid and continuous physical activity.	O strongly disagree	O disagree	O agree	O strongly agree
33. I have enough time to get my work done.	O strongly disagree	O disagree	O agree	O strongly agree
34. I am free from conflicting demands that others make.	O strongly disagree	O disagree	O agree	O strongly agree
35. My work requires long periods of intense concentration on the task.	O strongly disagree	O disagree	O agree	O strongly agree
36. My tasks are often interrupted before they can be completed, requiring attention at a later time.	O strongly disagree	O disagree	O agree	O strongly agree
37. My job is very hectic.	O strongly disagree	O disagree	O agree	O strongly agree
38. I am often required to work for long periods of time with my body in physically awkward positions.	O strongly disagree	O disagree	O agree	O strongly agree

15<u>3</u> 5

39. I am required to work for long periods with my head and arms in awkward positions.	O strongly disagree	O disagree	O agree	O strongly agree
40. Waiting on work from others often slows me down in my work.	O strongly disagree	O disagree	O agree	O strongly agree
41. People I work with are competent.	O strongly disagree	O disagree	O agree	O strongly agree
42. People I work with take a personal interest in me.	O strongly disagree	O disagree	O agree	O strongly agree
43. I am exposed to hostility or conflict from people I work with.	O strongly disagree	O disagree	O agree	O strongly agree
44. People I work with are friendly.	O strongly disagree	O disagree	O agree	O strongly agree
45. People I work with encourage each other to work together.	O strongly disagree	O disagree	O agree	O strongly agree
46. People I work with are helpful in getting the job done.	O strongly disagree	O disagree	O agree	O strongly agree
Answer these last questions only if you have a supervisor for the main work role you noted above.				
47. My supervisor is concerned about the welfare of those under him/her.	O strongly disagree	O disagree	O agree	O strongly agree
48. My supervisor pays attention to what I am saying.	O strongly disagree	O disagree	Oagree	O strongly agree
49. I am exposed to hostility or conflict from my supervisor.	O strongly disagree	O disagree	O agree	O strongly agree

50. My supervisor is helpful in getting the job done.	O strongly disagree	O disagree	O agree	O strongly agree
51. My supervisor is successful in getting people to work together.	O strongly disagree	O disagree	O agree	O strongly agree

	re asked to record your usual c	faily activities, and to answ		
In this questionnaire you a	•		er four questions about each a	tivity.
Complete the attached wor half-hour. For each half-h cooking, to bathing. If you	ksheets for a "typical work day our record the <u>main</u> activity y a do an activity for longer than	y" this week. Record your ou did during that half-hou a half-hour, write it down	activities from the time you w ur. An activity can be anything again for as long as you conti	ake up. Each row represents a from talking to a friend, to nue to do that activity.
Next to the activity columr of the questions for <u>each</u> a activities are work, daily liv you enjoy them.	<ul> <li>there are four columns with a ctivity by circling the number ing tasks, recreation, or rest, an</li> </ul>	a question at the head of ex of the most appropriate an nd to consider how well yc	ich column. After you have lis swer. Notice that the questions u do the activities, how import	ted your activities, answer all four ask you to consider whether your int they are to you, and how much
In the first question, <i>work</i> ( people, like household wor getting dressed or bathing. of your activities, please try sleeping at night.	does not necessarily mean that k, child care, schoolwork or v <i>Rest</i> includes taking a nap an t to respond to each one as acc	you are paid for the activit olunteering at a hospital. <i>L</i> id not doing anything in p urately as possible. You c	y. Work can include productiv Daily living tasks are those relat Inticular. Even if a question do to not need to answer the 4 que	e activities that are useful to other ed to your own self-care, such as es not seem appropriate for some stions for the hours you are
Ī	<u>selow is an EXAMPLE of hov</u>	v to complete the workshe	ets, which start on the next pa	ie.
	QUESTION 1 I consider this activity to be: 1 - work 2 - a daily living task	QUESTION 2 I think that I do this: I - very well 2 - well	QUESTION 3 For me, this activity: 1 - is very important 2 - is important	QUESTION 4 How much I enjoy this activity: I - I like it very much
Main Activity For the half hour beginning at:	3 - recreation 4 - rest	3 – about average 4 – poorly 5 – very poorly	3 - I can take it or leave it 4 - one I'd rather not do 5 - a total waste of time	<ul> <li>3 - I neither like it nor dislike it</li> <li>4 - I dislike it</li> <li>5 - I strongly dislike it</li> </ul>
7:00 a.m. Sleeping	1234	12345	1 2 3 4 5	1 2 3 4 5
7:30 Showening	1 (2) 3 4	1 (2) 3 4 5	(1) 2 3 4 5	1 (2) 3 4 5
8:00 breakfast	1 (2) 3 4	1 2 3 4 5	<u>(</u> ) 2 3 4 5	1 (2) 3 4 5
8:30 driving to work	<u>(</u> ) 2 3 4	1 2 3 4 5	1 (2) 3 4 5	1 2 (3) 4 5

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	QUESTION 1 Consider this activity to be:	QUESTION 2	QUESTION 3	QUESTION 4
	1 - WORK	l tunin mart do mus. 1 - very well	ror me, uns acuvuy: 1 – is very important	How much I enjoy this activity: 1 - 1 like it very much
:	2 - 4 UAUY INTING IASN 3 - recreation	z – well 3 – about average	2 – is important 3 – I can take it or leave it	2 – I like it 3 – I neither like it nor dislike it
En the hold build	4 – rest	4 - poorly	4 - one l'd rather not do	4 – I dislike it
ror me nail nour beginning at:		5 - very poorly	5 - a total waste of time	5-1 strongly dislike it
5:00 a.m.	1 2 3 4	1 2 3 4 5	12345	2 2 2 2
5:30	- 2 3 4	2 2 2 2	2 7 8 6 1	· · · ·
6:00	4 c -	1 2 3 4 5		
6.30				C + C 7 1
00.0	1 2 3 4	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
7:00	1234	12345	12345	12345
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8:00	1234	12345	1 2 3 4 5	1 2 3 4 5
8:30	1234	12345	1 2 3 4 5	1 2 3 4 5
9:00	1234	1 2 3 4 5	12345	1 2 3 4 5
9:30	1234	12345	12345	1 2 3 4 5
10:00	1234	12345	1 2 3 4 5	1 2 3 4 5
10:30	1234	12345	1 2 3 4 5	12345
11:00 а.т.	1234	12345	12345	1 2 3 4 5

N

	QUESTION 1 I consider this activity to be: 1 – work 2 – a daily living task	QUESTION 2   think that   do this:   - very well 2 - well	QUESTION 3 For me, this activity: 1 – is very important 2 – is important	QUESTION 4 How much I enjoy this activity: 1 – 1 like it very much
Main Activity For the half hour beginning at:	3 - recreation 4 - rest	3 – about average 4 – poorly 5 – very poorly	<ul> <li>3 - I can take it or leave it</li> <li>4 - one l'd rather not do</li> <li>5 - a total waste of time</li> </ul>	<ul> <li>2 - 1 mouth</li> <li>3 - 1 mouth</li> <li>4 - 1 dislike it</li> <li>5 - 1 strongly dislike it</li> </ul>
11:30 a.m.	1 2 3 4	12345	12345	12345
12:00 noon	1234	12345	12345	12345
12:30 p.m.	1234	12345	12345	12345
1:00	1 2 3 4	12345	1 2 3 4 5	12345
1:30	1 2 3 4	12345	12345	12345
2:00	1234	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
2:30	1234	12345	12345	1 2 3 4 5
3:00	1234	12345	12345	1 2 3 4 5
3:30	1 2 3 4	12345	12345	1 2 3 4 5
4:00	1234	12345	12345	1 2 3 4 5
4:30	1 2 3 4	1 2 3 4 5	12345	1 2 3 4 5
5:00	1234	12345	1 2 3 4 5	1 2 3 4 5
5:30	1234	12345	12345	1 2 3 4 5
6:00 р.т.	1234	12345	1 2 3 4 5	1 2 3 4 5
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	QUESTION 1 I consider this activity to be: 1 - work 2 - a daily living task 3 - recreation	QUESTION 2 I think that I do this: I - very well 2 - well 3 - about aversoe	QUESTION 3 For me, this activity: 1 - is very important 2 - is important 3 - 1 can take it or leave it	QUESTION 4 How much I enjoy this activity: 1 – 1 like it very much 2 – 1 like it
Main Activity For the half hour beginning at:	4 – rest	4 - poorly 5 - very poorly	5 - 1 can take it of reave it 5 - a total waste of time	<ul> <li>5 - 1 neturer like it nor dislike it</li> <li>4 - I dislike it</li> <li>5 - I strongly dislike it</li> </ul>
6:30 р.т.	1234	12345	12345	12345
7:00	1234	12345	12345	1 2 3 4 5
7:30	1234	12345	12345	12345
8:00	1234	12345	12345	1 2 3 4 5
8:30	1234	12345	12345	12345
9:00 p.m	1234.	12345	1 2 3 4 5	1 2 3 4 5
9:30	1 2 3 4	12345	12345	12345
10:00	1234	1 2 3 4 5	12345	12345
10:30	1234	12345	12345	1 2 3 4 5
11:00	1234	12345	12345	12345
11:30	1234	12345	12345	1 2 3 4 5
12:00 midnight	1 2 3 4	1 2 3 4 5	12345	12345
12:30 а.т.	1234	1 2 3 4 5	12345	12345

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# Your Comments on the Draft Survey about Paid and Unpaid Work

This packet has two parts: a questionnaire and an activity diary. Together, these are considered "the survey."

After you have completed the survey, your comments about it would be very helpful. If you have additional comments, please write them on the reverse side.

1. Were any questions especially unclear or difficult to answer? If yes which ones? (e.g. #7, #10).

____

2. Did any of the questions seem really dumb or irrelevant? If yes, which ones?

3. Were any of the questions insensitive or intrusive? If yes, which ones?

4. (a) Were the instructions for the questionnaire clear?

(b) Were the instructions for the activity diary clear?

5. Approximately how long did it take to complete this package?

6. Is there anything else you would like to tell us about the draft questionnaire and diary?

Thank you! Your assistance is very much appreciated.

### THE UNIVERSITY OF BRITISH COLUMBIA

### **APPENDIX 5**

School of Rehabilitation Sciences Faculty of Medicine T325 - 2211 Wesbrook Mall Vancouver, B.C. Canada V6T 2B5

Tel: (604) 822-7392 Fax: (604) 822-7624 Website: http://www.rehab.ubc.ca/srs.html

## A Study of Participation in Paid and Unpaid Work by Adults with Rheumatoid Arthritis

September, 1999

In the past you indicated interest in participating in research projects as a representative of someone with either mild or severe rheumatoid arthritis. We are writing to invite your participation in a project that involves answering some questions in order to study how people with RA participate in paid and unpaid work activities. Ultimately, this information will be useful in the design of rehabilitation and education programs aimed at helping people with arthritis maintain or improve their ability to engage in both paid and unpaid work.

The principal investigator is Catherine Backman, a senior instructor in Rehabilitation Sciences at UBC. She is conducting the project as part of her PhD studies in Health Care and Epidemiology, also at UBC. Dr. Chalmers is a co-investigator. The project title is "Participation in Paid and Unpaid Work by Adults with Rheumatoid Arthritis." The overall purpose of this project is to identify factors associated with participation in productive work activities by people with rheumatoid arthritis.

No clinic visits are required to participate in this study. The questionnaires are enclosed with this letter, and you are invited to answer them to the best of your ability and return them in the envelope provided. You are not obligated to complete the questionnaires. You have the right to refuse to participate or to omit individual questions. Refusal will not jeopardize your medical care.

The questionnaires will take about an hour to complete. By completing and mailing them, it is assumed that you have given consent to participate in the project. In order to assess the reliability of one part of the questionnaire, that part will be sent to you a second time, in about two weeks. If you choose to complete the second mailout, this section of the questionnaire will take an additional 20 minutes to complete.

### DR. BARRY KOEHLER

**APPENDIX 7** 

MD, FRCPC RHEUMATOLOGY CLINICAL PROFESSOR, UNIVERSITY OF BRITISH COLUMBIA

230-6091 GILBERT ROAD RICHMOND, BC V7C 5L9

Phone 604/273-8085 Fax 604/273-8043

## A Study of Participation in Paid and Unpaid Work by Adults with Rheumatoid Arthritis

I'm writing to invite your participation in a research project. The following information will help you decide if you are interested.

The project is a study of factors associated with participation in paid and unpaid work activities among adults with rheumatoid arthritis. Ultimately, this information will be useful in the design of rehabilitation and education programs aimed at helping people with arthritis maintain or improve their ability to engage in both paid and unpaid work.

The project is being conducted by Catherine Backman, a senior instructor at the School of Rehabilitation Sciences, University of British Columbia as part of her PhD studies in Health Care and Epidemiology. Dr. Andrew Chalmers is a co-investigator. Participants will be asked to complete questionnaires that ask about work activities (employment, housework, caregiving, volunteer work), and factors that may be related to their ability to do work activities. These factors include questions about arthritis, general health, functional and physical ability, and workplace issues. The survey will take about an hour to complete. All surveys will be anonymous (you are asked not to put your name on any page). They are only available in English.

To receive a questionnaire or further information about the study, please complete the enclosed reply form, and send it in the stamped, addressed envelope provided to Catherine Backman at UBC.

Your name and address has not been released to Ms Backman or anyone else associated with this project. You will only be contacted if you complete the enclosed reply form. You are free to ignore this request, and doing so will have no effect on your continuing medical care.

Thank you for considering this request.

Sincerely,

Dr. Barry Koehler

enclosure: reply form and envelope

# Participation in Paid and Unpaid Work by Adults with Rheumatoid Arthritis

# **REPLY FORM**

Thank you for considering the request to participate in this research project. By filling out the following information, you are requesting a survey. You are not obligated to complete and return the survey, if upon receipt you decide not to participate. Use the enclosed stamped, addressed envelope to return this form. If you would prefer more information about the project prior to completing this form, please call Catherine Backman at UBC, at 822-7409.

PLEASE PRINT

Name 🗆 Mr 🖸 Mrs 🖨 Ms	·
Address	· · · · · · · · · · · · · · · · · · ·
City	Postal Code
Telephone	

* * * * *

We acknowledge that not everyone invited to participate will be willing or able to do so. If you choose not to participate, you can still make a valuable contribution to the research project by answering the following questions. Your answers will help us to determine if there are any differences between the people who ask for questionnaires compared to those who do not. Do not fill in your name and address in the above section. Return this form in the reply envelope.

Check one: Male 🔾 Female 🔾

What year were you born?

What year was your rheumatoid arthritis diagnosed?

Are you currently employed? Yes 🗅 No 🗅

What is your main occupation?

Thank you for your assistance.

koehler

# THE UNIVERSITY OF BRITISH COLUMBIA

#### **APPENDIX 8**

School of Rehabilitation Sciences Faculty of Medicine T325 - 2211 Wesbrook Mall Vancouver, B.C. Canada V6T 2B5

Tel: (604) 822-7392 Fax: (604) 822-7624 Website: http://www.rehab.ubc.ca/srs.html

March 10, 2000.

Hello,

Recently your rheumatologist invited you to consider participating in a research project to identify the factors that help or hinder people's participation in paid and unpaid work. This letter and survey has been sent to you because you completed a reply form that was enclosed with your doctor's letter.

My name is Catherine Backman. I'm a senior instructor in Rehabilitation Sciences at UBC, and I'm conducting the project as part of my PhD studies in Health Care and Epidemiology, also at UBC. The project title is "**Participation in Paid and Unpaid Work by Adults with Rheumatoid Arthritis**." The overall purpose of this project is to identify factors associated with participation in productive work activities by people with rheumatoid arthritis. Ultimately, this information will be useful in the design of rehabilitation and education programs aimed at helping people with arthritis maintain or improve their ability to engage in both paid and unpaid work.

You are not obligated to complete and return the survey. You have the right to refuse to participate or to omit individual questions. Refusal will not jeopardize your medical care.

The questionnaires will take about an hour to complete. By completing and mailing them, it is assumed that you have given consent to participate in the project.

A stamped, addressed envelope is enclosed for you to return the questionnaires. You are asked to return them within 10 days. A pen is enclosed for your convenience – please keep it, as it is difficult to move through the postal system. The reply envelope has a code number on it that will be used to track how many surveys have been mailed out and returned, and to assist with sending reminders. The code cannot be used to identify who has completed the questionnaire.

## The University of British Columbia • School of Rehabilitation Sciences Participation in Paid and Unpaid Work by Adults with RA

- **A** Thank you for taking time to participate in this research study. Because everyone's experience with arthritis is different, your survey is important. Although it may look long, it should take less than an hour to complete.
- **A** The purpose of this study is to determine, on average, how much time people with arthritis spend on paid and unpaid work tasks, and to identify how their arthritis may affect their level of participation. The results will help improve rehabilitation and education programs aimed at assisting people with arthritis to maintain or improve their ability to pursue valued work activities.

## **A** In this study....

paid work refers to all types of employment, full-time, part-time, self-employment

unpaid work refers to productive activities for which you are not paid, such as:

- household work, for example: cleaning, cooking, laundry
- household maintenance, for example: yardwork, home repairs
- care-giving, for example: dressing a child, caring for someone ill or elderly
- errands, for example: shopping for groceries, paying the bills
- school, for example: attending classes & studying, but not leisure classes
- volunteer work, for example: at a hospital or for a charity organization

Paid and unpaid work are productive activities, and DO NOT include things you do to care for yourself (dressing, getting a haircut) or with your spare time (leisure, hobbies, recreation activities).

# **A** Section 1 •• Questions about Paid and Unpaid Work

Questions are listed in the left hand column. Respond in the right hand column, by checking  $[\checkmark]$  the bubble after the appropriate answer, or circling the appropriate rating where there is a rating scale, or filling in the blank.

1. Last week, did you do any unpaid housework, like cooking, cleaning, grocery shopping, or laundry for your household?	Yes O → For about how many hours? No O
<ol> <li>Last week, did you do any unpaid</li></ol>	Yes O
work to maintain or improve your	→ For about how many hours?
home, yard, or automobile?	No O

3.	Last week, did you provide any child care or caregiving to another member of your household?	Yes O → For about how many hours? No O
4.	Last week, did you do any volunteer work for an organization in your community?	Yes O → For about how many hours? No O
5.	Last week, did you spend any time going to school and doing schoolwork (studying)?	Yes O → For about how many hours? No O
6.	Last week, did you do any paid work at a job or business?	Yes O → For about how many hours? No O → In what year were you last employed? 
7.	<ul> <li>a) What do you consider to be your main occupation? That is, the paid or unpaid work activity that takes most of your time and energy. (print it on the lines in the next column)</li> <li>b) Which of the following best describes this occupation?</li> </ul>	household work ○ full-time employee ○ part-time employee ○ self-employed ○ student ○ volunteer ○ retired ○ other ○ → specify:

<ol> <li>On a scale of 1 to 10, how satisfied are you in your ability to perform your main work activity? (circle a number)</li> </ol>	<u>1 2 3 4 5 6 7 8 9 10</u> very very dissatisfied sati	y sfied
9. How satisfied are you with the balance of time you spend on work, self-care, leisure, and rest? (circle a number)	<u>1 2 3 4 5 6 7 8 9 10</u> very very dissatisfied satis	y sfied
<ul><li>10. At the end of the day, how satisfied are you that you have accomplished what you had set out to do? (circle a number)</li></ul>	<u>1 2 3 4 5 6 7 8 9 10</u> very very dissatisfied satis	y sfied
11. Do you work as many hours per week as you would like?	Yes $\bigcirc \rightarrow$ Go to # 14. No $\bigcirc$ $\rightarrow$ I work more hours than I want to $\rightarrow$ I work less hours than I want to	0 0
<ul><li>12. If you work LESS than you would like, why?</li><li>[Not applicable? Skip to #13.]</li></ul>	because of my arthritis O because of another illness O other personal responsibilities O other household responsibilities O could only find part-time work O another reason O specify:	
<ul><li>13. If you work MORE than you would like, why?</li><li>[Not applicable? Skip to #14.]</li></ul>	my type of work requires it O financial reasons O don't want to be considered unable to do the work O part-time hours not available O another reason O specify:	

14. Do you need to travel outside your home in order to do your work?	Yes, I regularly commute to work Yes, I do errands outside the home No → Skip questions #15 - 17, go to #18.			
15. How do you travel?	transit O own car O carpool O walk O bicycle O handydart O other O → specify:			
16. How long does it take, on average, to commute?	hours per day			
17. On a scale of 1 to 10, how difficult do you consider your commute? (circle one number)	1       2       3       4       5       6       7       8       9       10         very       not at all       difficult       difficult			

The next few questions relate to your <u>main work</u>, the one you wrote down in question #7.

If you consider yourself to have "two jobs,"

- e.g., a mom or who also works outside the home, or
  - you have a paid job plus you go to school or do most of the housework,

answer these next questions keeping in mind your <u>main job</u> listed in question #7; you can <u>answer them again for your second job</u> on the extra copy at the end of the survey.

Check  $[\checkmark]$  the bubble indicating the best response.

18. My work requires that I learn new things.	O strongly disagree	O disagree	O agree	O strongly agree
19. My work involves a lot of repetitive tasks.	O strongly disagree	. O disagree	O agree	O strongly agree

20. My work requires me to be creative.	O strongly disagree	O disagree	O agree	O strongly agree
21. My work allows me to make a lot of decisions on my own.	O strongly disagree	O disagree	O agree	O strongly agree
22. My work requires a high level of skill.	O strongly disagree	O disagree	O agree	O strongly agree
23. I have very little freedom to decide how I do my work.	O strongly disagree	O disagree	O agree	O strongly agree
24. I get to do a variety of different things in my work.	O strongly disagree	O disagree	O agree	O strongly agree
25. I have a lot of say about what happens in my work.	O strongly disagree	O disagree	O agree	O strongly agree
26. I have an opportunity to develop my own special abilities.	O strongly disagree	O disagree	O agree	O strongly agree
27. My work requires me to work very fast.	O strongly disagree	O disagree	O agree	O strongly agree
28. My work requires me to work very hard.	O strongly disagree	O disagree	O agree	O strongly agree
29. My work requires a lot of physical effort.	O strongly disagree	O disagree	O agree	O strongly agree
30. I am not asked to do an excessive amount of work.	O strongly disagree	O disagree	O agree	O strongly agree

, o co a ca c	************			*****************************
31. I am often required to move or lift very heavy loads in my work.	O strongly disagree	O disagree	O agree	O strongly agree
32. My work requires rapid and continuous physical activity.	O strongly disagree	O disagree	O agree	O strongly agree
33. I have enough time to get my work done.	O strongly disagree	O disagree	O agree	O strongly agree
34. I am free from conflicting demands that others make.	O strongly disagree	O disagree	O agree	O strongly agree
35. My work requires long periods of intense concentration on the task.	O strongly disagree	O disagree	O agree	O strongly agree
36. My tasks are often interrupted before they can be completed, requiring attention at a later time.	O strongly disagree	O disagree	O agree	O strongly agree
37. My job is very hectic.	O strongly disagree	O disagree	O agree	O strongly agree
38. I am often required to work for long periods of time with my body in physically awkward positions.	O strongly disagree	O disagree	O agree	O strongly agree
39. I am required to work for long periods with my head and arms in awkward positions.	O strongly disagree	O disagree	O agree	O strongly agree
40. Waiting for work from others often slows me down in my work.	O strongly disagree	O disagree	O agree	O strongly agree
41. People I work with are competent.	O strongly disagree	O disagree	O agree	O strongly agree

42. People I work with take a personal interest in me.	O strongly disagree	O disagree	O agree	O strongly agree
43. I am exposed to hostility or conflict from people I work with.	O strongly disagree	O disagree	O agree	O strongly agree
44. People I work with are friendly.	O strongly disagree	O disagree	O agree	O strongly agree
45. People I work with encourage each other to work together.	O strongly disagree	O disagree	O agree	O strongly agree
46. People I work with are helpful in getting the job done.	O strongly disagree	O disagree	agree	O strongly agree

Do you have a supervisor or boss for your main work activity? Yes  $O \rightarrow$  Answer questions #47 to 51.

 $\rightarrow$  Skip to page 8. No O

47. My supervisor is concerned about the welfare of those under him/her.	O strongly disagree	O disagree	O agree	O strongly agree
48. My supervisor pays attention to what I am saying.	O strongly disagree	O disagree	O agree	O strongly agree
49. I am exposed to hostility or conflict from my supervisor.	O strongly disagree	O disagree	O agree	O strongly agree
50. My supervisor is helpful in getting the job done.	O strongly disagree	O disagree	O agree	O strongly agree
51. My supervisor is successful in getting people to work together.	O strongly disagree	O disagree	O agree	O strongly agree
### **a** Section 2 •• How Arthritis Affects You

In this section, we'd like to know about the effect of arthritis on you and your ability to do everyday activities,

First, we'd like to know how your **arthritis pain** affects you. For each of the following questions, please circle the number which corresponds to your certainty that you can now, at this moment, perform the following tasks.

1.	How certain are you that you can decrease your pain <u>quite a bit</u> ? (circle a number)	10 very unce	20 / ertai	30 n	и 40 п	50 node cer	60 ratel tain	70 y	80	1 90 cei	100 very rtain
2.	How certain are you that you can continue most of your daily activities? (circle a number)	10 very unc	20 / ertai	1 30 n	40 n	50 node cer	60 erate tain	1 70 ly	80	90 ce	100 very rtain
3.	How certain are you that you can keep arthritis pain from interfering with your sleep?	10	20	30	-1 40	50	60	70	1 80	л 90	ר 100
	sicep:	very unc	y ertai	n	n	node cer	tain	ly		ce	very rtain
4.	How certain are you that you can make a <u>small-to-moderate</u> reduction in your arthritis pain by using methods other than taking extra medication?	very unc 10 very unc	y ertai 20 y ertai	n 1 30 n	n 	node cer 50 node cer	rate tain 1 60 crate tain	ly  70 ly	80	ce 1 90 ce	very rtain 100 very rtain

Next, we'd like to know how confident you are in performing certain daily activities.

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For each of the following questions, please circle the number which corresponds to your certainty that you can perform tasks as of **now, without** assistive devices or help from another person. Please consider what you **routinely** can do, not what would require a single extraordinary effort.

1.	Walk 100 feet on flat ground in 20 seconds? (circle a number)	T 10 ver unc	20 y ertai	30 n	40 n	50 node cer	60 Fate tain	1 70 ly	80	90 c	100 very ertain	
2.	Walk 10 steps downstairs in 7 seconds?	۲ 10	1 20	Т 30	1 40	50	60	70	1 80	ا 90	 100	
		ver unc	y ertai	n	n.	node cer	rate. tain	ly		ce	very rtain	
3.	Get out of an armless chair quickly, without using your hands for support?	۲ 10	1 20	T 30	1 40	T 50	Г 60	70		90	□ 100	
		very vertain		n	moderately certain					very certain		
4.	Button and unbutton 3 medium-size buttons in a row in 12 seconds?	۲ 10	20	T 30	40	50	60	70	1 80	1 90	۔ 100	
		very unc	/ ertai:	n	n	node cer	ratel tain	y		ce	very rtain	
5.	Cut 2 bite-size pieces of meat with a knife and fork in 8 seconds?	 10		<del>ا</del> 30		50	60	70	80	90	ר 100	
		very unce	ertai	n	moderately certain					very certain		
6.	Turn an outdoor faucet all the way on and all the way off?	٦ 10	1 20	٦ 30	T 40	50	Т 60	T 70	T 80	1 90	ר 100	
		very unce	, ertaii	n	m	ode: cert	ratel tain	у		cei	very rtain	
7.	Scratch your upper back with both your right and left hands?	۲ 10	Т 20	T 30	T 40	50	60	70	1 80	90	ר 100	
		very unce	ertair	1	m	oder cert	ratel ain	у		cei	very tain	

# AS OF NOW, HOW CERTAIN ARE YOU THAT YOU CAN:

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### AS OF NOW, HOW CERTAIN ARE YOU THAT YOU CAN:

8.	Get in and out of the passenger side of a car without assistance from another person and without physical aids?	10 ver unc	20 y ertai	30 n	40 n	50 node cer	60 ratel tain	70 Iy	80	90 cei	100 very rtain
9.	Put on a long-sleeve front-opening shirt or blouse (without buttoning) in 8 seconds?	10 very unc	20 20 v ertai	30 n	1 40 n	50 node cer	60 ratel tain	70 y	80	90 cei	100 very tain

Now, we'd like to know how you feel about your ability to control your **arthritis symptoms**. Please circle the number which corresponds to the certainty that you can **now**, at this moment, perform the following activities or tasks.

1.	<u>How certain</u> are you that you can control your fatigue? (circle a number)	10 ver unc	20 y ertai	30 n	40 n	50 node cer	60 ratel tain	70 70	80	90 Ce	100 very ertain
2.	<u>How certain</u> are you that you can regulate your activity so as to be active without aggravating your arthritis?	10 ver unc	20 y ertai	1 30 n	т 40 п	50 node cer	60 frate tain	70 İy	80	90 cei	100 very rtain
3.	How certain are you that you can do something to help yourself feel better if you are feeling blue?	□ 10 ver unc	20 y ertai	30 n	40 n	50 node cer	60 ratel tain	70 1 y	80	90 cei	100 very rtain
4.	As compared with other people with arthritis like yours, <u>how certain</u> are you that you can manage arthritis pain during your daily activities?	10 very unc	20 y ertai	30 n	40 • n	50 node cer	60 ratel tain	т 70 У	80	90 cei	☐ 100 very tain

5. <u>How certain</u> are you that you can manage your arthritis symptoms so that you can do the things you enjoy doing?	۲ 10 ver und	20 y certai	30 in	40 п	50 node cer	60 frate tain	70 Jy	80	90 ce	100 very rtain
6. <u>How certain</u> are you that you can deal with the frustration of arthritis?	۲ 10 ver unc	20 y certai	30 in	40 n	50 node cer	60 ratel tain	і 70 У	80	90 ce	100 very rtain

# ষ্ব Section 3 •• About Your General Health Status

This section contains questions about your general health and your everyday functional ability. It actually contains questions from another standardized survey, so that we can compare results of this study with other studies done in the past. Some of the questions are very similar to those you've already answered, but we need to ask them again in order to make valid comparisons with other research.

First, we'd like to know **how much difficulty** you have with a few everyday tasks. Check  $[\sqrt{}]$  the box on the chart below to indicate the ONE best answer to each question.

Ar	e you able to:	without difficulty	with some difficulty	with much difficulty	unable to do
1.	dress yourself, including tying shoelaces and doing buttons?				
2.	get in and out of bed?			,	
3.	lift a full cup or glass to your mouth?				
4.	walk outdoors on flat ground?				
5.	wash and dry your entire body?				
6.	bend down to pick up clothing from the floor?				
7.	turn faucets (taps) on and off?		*****		
8.	get in an out of a car?				

### Indicate the best answer to each of the following questions.

1.	In general	, would you	say your health is:	(circle one number)
----	------------	-------------	---------------------	---------------------

1	2	3	4	5
Excellent	Very Good	Good	Fair	Poor

2. <u>Compared to one year ago</u>, how would you rate your health in general <u>now</u>?

(circle one)

Much better now than one year ago	1
Somewhat better now than one year ago	2
About the same as one year ago	3
Somewhat worse than one year ago	4
Much worse now than one year ago	5

3. The following items are about activities you might do during a typical day. Does your health now limit you in these activities. If so, how much?

·····		cle one number	on each line)	
	ACTIVITIES	yes, limited a lot	yes, limited a little	no, not limited at all
а,	Vigorous activities, such as running, lifting heavy objects, participating in strenuous sports	1	2	3
b.	Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling or playing golf	1	2	3
c.	Lifting or carrying groceries	1	2	3
d.	Climbing several flights of stairs	1	. 2	3
e.	Climbing one flight of stairs	1	2	3
f.	Bending, kneeling, or stooping	1	2	3
g.	Walking more than a kilometre	1	2	3
h.	Walking several blocks	1	2	3
i.	Walking one block	1	2 ·	3
j.	Bathing or dressing yourself	1	2	3

4. During the **past week**, have you had any of the following problems with your work or regular daily activities as <u>a result of your physical health</u>?

		(circle one num	ber on each line)
		YES	NO
a.	Cut down on the <b>amount of time</b> you spent on work or other activities	1	2
b.	Accomplished less than you would like	1	2
с.	Were limited in the <b>kind</b> or other activities	1	_ 2
d.	Had <b>difficulty</b> performing the work or other activities (for example, it took extra effort)	1	2

5. During the **past week**, have you had any of the following problems with your work or other regular daily activities <u>as a result of any emotional problems</u> (such as feeling depressed or anxious)?

		(circle one num	ber on each line)
		YES	NO
a.	Cut down on the <b>amount of time</b> you spent on work or other activities	1	2
b.	Accomplished less than you would like	1	2
с.	Didn't do work or other activities as carefully as usual	1	2

6. During the **past week**, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbors or groups? (circle one number)

1	2	3	4	5
Not at all	Slightly	Moderately	Quite a bit	Extremely

7. How much <u>bodily</u> pain have you had during the <u>past week</u>?

	1	2	3	4	5	6
	None	Very Mild	Mild	Moderate	Severe	Very Severe
8	During t	he nast wook h	ow much d	id noin interform	:'sh	·

(including both work outside the home and housework)?

1	2	3	4	5
Not at all	A little bit	Moderately	Quite a Bit	Extremely

9. These questions are about how you feel and how things have been with you <u>during</u> <u>the past week</u>. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the past week –

	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
a. Did you feel full of pep?	1	2	3	4	5	6
b. Have you been a very nervous person?	1	2	3	4	5	6
c. Have you felt so down in the dumps that nothing could cheer you up?	1	2	3	4	5	6
d. Have you felt peaceful and calm?	1	2	3	4	5	6
e. Did you have a lot of energy?	1	2	3	4	5	6
f. Have you felt downhearted and blue?	1	2	3	4	5	6
g. Did you feel worn out?	1	2	3	4	5	6
h. Have you been a happy person?	1	2	3	4	5	6
i. Did you feel tired?	1	2	3	4	5	6

10. During the **past week**, how much of the time has your <u>physical or emotional health</u> interfered with your social activities (like visiting with friends, relatives, etc.)? (circle one number)

1	2	3	4	5
All	Most	Some	A little	None
of the time	of the time	of the time	of the time	of the time

## 11. How TRUE of FALSE is each of the following statements for you?

(circle one number on each line)						
	Definitely True	Mostly True	Don't Know	Mostly False	Definitely False	
a. I seem to get sick a little easier than other people	1	2	3	4	5	
b. I am as healthy as anybody I know	1	2	3	4	5	
c. I expect my health to get worse	1	2	3	4	5	
d. My health is excellent	1	2	3	4	5	

12. These questions ask about the support you have available to you right now.

······		••••••••	(	<u>(circle c</u>	ne n	umber	on ea	ch line)
a.	There is a special person who is around when I am in need.	1 strongly <b>disagree</b>	2	3	4	5	6 s1	7 trongly <b>agree</b>
b.	There is a special person with whom I share my joys and sorrows.	1 strongly <b>disagree</b>	2	3	4	5	6 s1	7 rongly <b>agree</b>
c.	My family really tries to help me.	1 strongly <b>disagree</b>	2	3	4	5	6 s1	7 rongly <b>agree</b>

		*************************************		*************		
d.	I get the emotional help and support I need from my family.	1 2 strongly <b>disagree</b>	3	4	5	6 7 strongly <b>agree</b>
е.	I have a special person who is a real source of comfort to me.	12 strongly disagree	3	4	5	6 7 strongly <b>agree</b>
f.	My friends really try to help me.	12 strongly disagree	3	4	5	6 7 strongly <b>agree</b>
g.	I can count on my friends when things go wrong.	12 strongly <b>disagree</b>	3	4	5	6 7 strongly <b>agree</b>
h.	I can talk about my problems with my family.	12 strongly <b>disagree</b>	3	4	5	6 7 strongly <b>agree</b>
i.	I have friends with whom I can share my joys and sorrows.	12 strongly <b>disagree</b>	3	4	5	6 7 strongly <b>agree</b>
j.	There is a special person in my life who cares about my feelings.	12 strongly <b>disagree</b>	3	4	5	6 7 strongly <b>agree</b>
k.	My family is willing to help me make decisions.	12 strongly <b>disagree</b>	3	4	5	6 7 strongly <b>agree</b>
L	I can talk about my problems with my friends.	12 strongly <b>disagree</b>	3	4	5	6 7 strongly <b>agree</b>

Thank you for your patience and persistence!

There are only a few more questions to go, please go to the next page...

### **A** Section 4: A Little bit About You

Remember, this information is strictly confidential, and remains anonymous because you do not put your name on the survey.

1. What year were you diagnosed with rheumatoid arthritis?

2. Make a mark [X] on the line below to indicate how active your RA is at this time.

Not at all active	The most
(in remission)	active it has
	ever been

3. Make a mark [X] on the line below to indicate the amount of pain resulting from your RA at this time.

No pain at	Pain as bad
all.	as can be.

4. Make a mark [X] on the line below to indicate the amount of fatigue (tiredness) you are experiencing at the present time.

No fatigue at	 Most severe
all.	fatigue ever.

5. What medication(s) are you taking for your RA? (please copy the name from your prescription label).

6. What year were you born? ______ 7. Check one: □ male □ female
8. Your marital status: □ married living with a partner widowed □ separated/divorced never married

(a bad flare)

- 9. How many people live in your household? _____ number of adults _____ # children under 18 years
- 10. We know that questions about household income are sensitive to some people. We ask this question because engaging in paid and unpaid work may be related to the economic necessity. Considering all sources, what was your approximate annual household income last year?
  - less than \$10,000
     \$20,001 to \$30,000
     \$40,001 to \$50,000
     \$60,001 to \$70,000

\$10,001 to \$20,000
 \$30,001 to \$40,000
 \$50,001 to \$60,000
 more than \$70,000

11. What are the sources of income for your household? (check all that apply)

- your employment income
- a family member's employment income
- your old age, union, or employer's pension plan
- a family member's old age, union, or employer's pension plan

**u** your disability pension

a family member's disability pension

your unemployment insurance

a family member's unemployment insurance

- family savings & investments (e.g., RRSPs)
- other sources:

## 12. What is the **highest** level of formal education you completed?

less than grade 9

some high school

- high school graduate
- some college/university or trade school
- trade school or vocational school graduate (diploma/certificate)
- university graduate (bachelor's degree)

master's or doctoral degree

A Is there anything else you'd care to tell us about your work or your arthritis?

 Thank you very much for your assistance. The results of this study will be useful for occupational therapists, physical therapists, social workers and other health care providers to improve services and programs for people with arthritis.

 Please put your completed survey in the envelope provided and mail it as soon as possible.

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if you have misplaced the envelope, send the survey to

Catherine Backman School of Rehabilitation Sciences The University of British Columbia T325 – 2211 Wesbrook Mall Vancouver, BC V6T 2B5

questions about this research project? write to me at the above address or telephone 604-822-7409 e-mail backman@rehab.ubc.ca OPTIONAL questions for people with two major paid or unpaid work roles.

8

IF you have TWO main occupations, you can elect to answer the following questions again, as they relate to your second job.

If you DO NOT have TWO main occupations: STOP! The questionnaire is over. 8

Write down the job you are thinking of here: P

Chec	k [1] the bu	bble indication	ng the be	st response
18. My work requires that I learn new things.	O strongly disagree	O disagree	O agree	O strongly agree
19. My work involves a lot of repetitive tasks.	O strongly disagree	O disagree	O agree	O strongly agree
20. My work requires me to be creative.	O strongly disagree	O disagree	O agree	O strongly agree
21. My work allows me to make a lot of decisions on my own.	O strongly disagree	O disagree	O agree	O strongly agree
22. My work requires a high level of skill.	O strongly disagree	O disagree	agree	O strongly agree
23. I have very little freedom to decide how I do my work.	O strongly disagree	O disagree	O agree	O strongly agree
24. I get to do a variety of different things in my work.	O strongly disagree	O disagree	O agree	O strongly agree
25. I have a lot of say about what happens in my work.	O strongly disagree	O disagree	O agree	O strongly agree
26. I have an opportunity to develop my own special abilities.	O strongly disagree	O disagree	O agree	O strongly agree

	***********************************	******		
27. My work requires me to work very fast.	O strongly disagree	O disagree	O agree	O strongly agree
28. My work requires me to work very hard.	O strongly disagree	O disagree	O agree	O strongly agree
29. My work requires a lot of physical effort.	O strongly disagree	O disagree	O agree	O strongly agree
30. I am not asked to do an excessive amount of work.	O strongly disagree	O disagree	O agree	O strongly agree
31. I am often required to move or lift very heavy loads in my work.	O strongly disagree	O disagree	O agree	O strongly agree
32. My work requires rapid and continuous physical activity.	O strongly disagree	O disagree	O agree	O strongly agree
33. I have enough time to get my work done.	O strongly disagree	O disagree	O agree	O strongly agree
34. I am free from conflicting demands that others make.	O strongly disagree	O disagree	O agree	O strongly agree
35. My work requires long periods of intense concentration on the task.	O strongly disagree	O disagree	O agree	O strongly agree
36. My tasks are often interrupted before they can be completed, requiring attention at a later time.	O strongly disagree	O disagree	O agree	O strongly agree
37. My job is very hectic.	O strongly disagree	O disagree	O agree	O strongly agree

<b>*</b> ***********************************	** **********			
38. I am often required to work for long periods of time with my body in physically awkward positions.	O strongly disagree	O disagree	O . agree	O strongly agree
39. I am required to work for long periods with my head and arms in awkward positions.	O strongly disagree	O disagree	O agree	O strongly agree
40. Waiting for work from others often slows me down in my work.	O strongly disagree	O disagree	O agree	O strongly agree
41. People I work with are competent.	O strongly disagree	O disagree	O agree	O. strongly agree
42. People I work with take a personal interest in me.	O strongly disagree	O disagree	O agree	O strongly agree
43. I am exposed to hostility or conflict from people I work with.	O strongly disagree	O disagree	O agree	O strongly agree
44. People I work with are friendly.	O strongly disagree	O disagree	O agree	O strongly agree
45. People I work with encourage each other to work together.	O strongly disagree	O disagree	O agree	O strongly agree
46. People I work with are helpful in getting the job done.	O strongly disagree	O disagree	O agree	O strongly

Do you have a supervisor or boss for the work activity you've been thinking of above?

Yes  $\bigcirc$   $\rightarrow$  Answer questions #47 to 51.

No  $\bigcirc$   $\rightarrow$  Stop. You're finished with the questionnaire.

47. My supervisor is concerned about the welfare of those under him/her.	O strongly disagree	O disagree	O agree	O strongly agree
48. My supervisor pays attention to what I am saying.	O strongly disagree	O disagree	O agree	O strongly agree
49. I am exposed to hostility or conflict from my supervisor.	O strongly disagree	O disagree	O agree	O strongly agree
50. My supervisor is helpful in getting the job done.	O strongly disagree	O disagree	O agree	O strongly agree
51. My supervisor is successful in getting people to work together.	O strongly disagree	O disagree	O agree	O strongly agree

INSTRUCTIONS:		DIARY	<b>OF ACTIVITIES FOR O</b>	NE DAY		
In this questionna	aire you are	e asked to record your usual d	aily activities, and to answ	er four questions about each a	ctivity.	
Complete the atta half-hour. For ea cooking, to bathin	ached work ach half-ho ng. If you	sheets for a "typical work day our record the main activity yo do an activity for longer than	" this week. Record your ou did during that half-hou a half-hour, write it down	activities from the time you w r. An activity can be anything again for as long as you conti	ake up. Each row represents a from talking to a friend, to nue to do that activity.	
Next to the activit of the questions for activities, and to c	ty column, or <u>each</u> act consider ho	there are four columns with a tivity by circling the number cow well you do them, how imp	question at the top of each of the most appropriate ans portant they are to you, and	column. After you have liste wer. Notice that the questions how much you enjoy them.	d your activities, answer all four s ask you to categorize the	
In the first questic other caregiving, as getting dressed events and similar some of your activ	on, paid w school, vol or bathing r activities. vities, pleas	ork includes all types of paid unteer work, and services you , getting your hair cut at the b . <u>Rest</u> includes taking a nap an se try to respond to each one a E: **You do not need to ans	jobs, including self-employ provide to others. <u>Person</u> arber shop or salon. <u>Recr</u> nd not doing anything in p as accurately as possible. wer the 4 questions for th	/ment. <u>Unpaid work</u> includes al/self care tasks are those rel eation refers to leisure, sports, articular. Even if a question d e hours you are sleeping at n	s household work, child care and ated to your own self-care, such socializing, attending cultural oes not seem appropriate for <b>ight.</b>	
	Bel	low is an EXAMPLE of how	to complete the worksheet	s, which start on the next pag		
		QUESTION 1 I consider this activity to be:	QUESTION 2 I think that I do this:	QUESTION 3 For me, this activity:	QUESTION 4 How much I enjoy this activity:	
	/	1 – paid work 2 – unpaid work	l – very well 2 – well	1 – is very important 2 – is important	1 – I like it very much	
Rear the half hour beginning	÷	3 – personal/self care 4 – recreation	3 – about average 4 – poorly	3 – I can take it or leave it 4 – one l'd rather not do	<ul> <li>2 - 1 like it</li> <li>3 - I neither like it nor dislike it</li> <li>4 - I dislike it</li> </ul>	
7:00 a.m. Sleethi				5 - a total waste of time	5 – I strongly dislike it	
7:30 Shower/d	ress	1 2 (3) 4 5			1 2 3 4 5 	
8:00 make brue	Jefast	1 (2) 3 4 5	1 2 (3) 4 5	1 2 (3) 4 5	1  2  3  4  5 1 2 (3) 4 5	
8:30 drive leids 1	to School	C1 (D) 3 4 5	1 2 (3) 4 5	1/(2) 3 4 5	1 (2) 3 4 5	
idapted/sept99						-

	QUESTION 1 I consider this activity to he:	QUESTION 2 1 think that 1 do this:	QUESTION 3 For marchine activities	QUESTION 4
	1 – paid work	- verv well	t or me, uns acuvity: 1 – is very important	How much I enjoy this activity:
	2 – unpaid work	2 – well	2 - is important 2 - is important	1 – 1 like it very much 2 – 1 like it
Main Activity	3 – personal/self care	3 – about average	3 – I can take it or leave it	3 - 1 neither like it nor dislike it
For the half hour beginning at	4 - Iccl calloll 5 root	4 - poorly	4 – one l'd rather not do	4 – I dislike it
	<b>J</b> = 1081	o – very poorly	5 – a total waste of time	5 – I strongly dislike it
5.00 a m	2 2 2 2	1 7 7 7		
		C 7 C 7 I	1 2 3 4 5	1 2 3 4 5
5:30	2 4 5 6 1	2 7 C L		
		C + C 7 I	1 2 3 4 5	12345
6:00	1 2 3 4 5	12345	1 2 3 4 5	12345
6:30	2 7 2 C 1	2 7 C C I		
			1 2 3 4 5	1 2 3 4 5
7:00	12345	1 2 3 4 5	12345	1 2 3 4 5
7:30	12345	1 2 3 4 5		
				0 7 7 7 7 1
8:00 .	1 2 3 4 5	1 2 3 4 5	12345	12345
8:30	12345	1 2 3 4 5	1 2 3 4 5	
9:00	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
9:30	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
10:00	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5	1 2 2 4 5
10:30	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
11:00 a.m.	1 2 3 4 5	12345	1 2 3 4 5	12345

	QUESTION I I consider this activity to be: 1 - naid work	QUESTION 2 I think that I do this:	QUESTION 3 For me, this activity:	QUESTION 4 How much I enjoy this activity:
	2 – unpaid work	1 - very well 2 - well	l – Is very important 2 – is important	1 – 1 like it very much 2 – 1 like it
Main Activity	3 – personal/self care 4 – recreation	3 – about average 4 – poorly	3 – I can take it or leave it 4 – one I'd rather not do	3 - 1 neither like it nor dislike it
For the half hour beginning at:	5 – rest	5 – very poorly	5 - a total waste of time	5 – I strongly dislike it
11:30 a.m.	12345	12345	12345	2 2 2 2
12:00 noon	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5	
12:30 р.т.	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
1:00	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
1:30	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
2:00	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
2:30	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
3:00	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
3:30	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
4:00	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
4:30	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
5:00	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
5:30 p.m.	12345	12345	1 2 3 4 5	1 2 3 4 5
19				

3

 $\mathfrak{C}$ 

	QUESTION 1 I consider this activity to be:	QUESTION 2 I think that I do this:	QUESTION 3 For me, this activity:	QUESTION 4 How much I enjoy this activity:
	1 - paid work 2 - unpaid work	l – very well 2 – well	l – is very important 2 – is important	1 – 1 like it very much
Main Activity	3 – personal/self care 4 – recreation	3 – about average	3 – I can take it or leave it	2 - 1 like it $3 - 1$ neither like it nor dislike it
For the half hour beginning at:	5 – rest	5 – very poorly	<ul> <li>4 - one I d rather not do</li> <li>5 - a total waste of time</li> </ul>	4 – I dislike it 5 – I strongly dislike it
6:00 p.m.	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
6:30	12345	1 2 3 4 5	1 2 3 4 5	1 2 2 5
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7:00	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
7:30	1 2 3 4 5	12345	12345	1 2 3 4 5
8:00	12345	12345	12345	1 2 3 4 5
8:30	1 2 3 4 5	1 2 3 4 5		
0.0				C + C 7 1
			1 2 3 4 5	1 2 3 4 5
9:30	1 2 3 4 5	1 2 3 4 5	12345	12345
10:00	1 2 3 4 5	12345	1 2 3 4 5	1 2 3 4 5
10:30	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
11:00	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5	
11:30	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
12:00 midnight	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5	2 - C
194		- - 1		C + C 7 I

	QUESTION 1 I consider this activity to be-	QUESTION 2 Lthink that Life thin:	QUESTION 3	QUESTION 4
	I – paid work	l – very well	For me, uns activity: 1 – is very important	How much I enjoy this activity: I – I like it very much
	2 – unpaid work	2 – well	2 – is important	2 – 1 like it
Main Activity	3 – personal/self care	3 – about average	3 – I can take it or leave it	3 – I neither like it nor dislike it
For the half hour beginning at:	4 - recreation 5 - rest	4 – poorly 5 – verv noorly	4 – one l'd rather not do	4 – I dislike it
		frond fra.	J – a lulal waste of time	5 – I strongly dislike it
12:30 a.m.	2 4 5 6 1			
		C + C Z I	1 2 3 4 5	1 2 3 4 5
l:00 a.m.	2 7 2 6 1	2 7 7 7 7 7		
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1:30	2 4 5 1			
			1 2 3 4 5	1 2 3 4 5
2:00	1 2 3 4 5	1 2 3 4 5	12345	2 7 S
2:30	1 2 3 4 5	1 2 3 4 5	12345	1 2 3 4 5
Second				
<b>M</b> .c	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5	1.2345
3:30	2 7 2 7	1 - -		
		C + C 7 I	1 2 3 4 5	1 2 3 4 5
4:00	2 2 2 5			
			1 2 3 4 5	1 2 3 4 5
4:30	2 1 2 1 5	2 7 7 7		
		0 4 0 7 1	1 2 3 4 5	1 2 3 4 5
5:00 a.m.	12345	1 2 3 4 5	2 4 5	
				0 7 7 7 1

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Appendix 9

The University of British Columbia School of Rehabilitation Sciences T325 - 2211 Wesbrook Mall, Vancouver, BC V6T 2B5 Recently, a survey was sent to you as part of a study on Participation in Paid and Unpaid Work by Adults with Rheumatoid Arthritis (RA). If you have already completed and mailed the survey, please accept my sincere thanks. If you haven't yet had the chance to do so, please consider completing it today. Every survey is important to help us understand the factors associated with people's ability to participate in household work, employment, and related activities. Of course, you are under no obligation to participate. If by some chance you did not receive the survey or it has been misplaced, please give me a call at UBC, at (604) 822-7409, or by e-mail at backman@rehab.ubc.ca, and I will have another copy sent to you immediately.

Please know that your participation in this project is greatly appreciated.

Sincerely,

Catherine Backman

#### Appendix 10 Formulae for Calculating Sub-scale Scores

The page and item numbers cited in each formula correspond to the page numbers and item numbers in the final survey (Appendix 8).

1. Sub-scales from Karasek's Job Content Questionnaire (JCQ)

These items are in Section 1 of the survey, pages 4 through 7.

- a.  $\frac{\text{Skill Discretion}}{[Q18 + Q20 + Q22 + Q24 + Q26 + (5 Q19)] \times 2}$
- b. <u>Decision Authority</u> [Q21 + Q25 + (5 - Q23)] x 4
- c. <u>Psychological Demand</u> [ $(Q27 + Q28) \times 3 + (15 - (Q30 + Q33 + Q34))$ ] x 2
- d. <u>Physical Demand</u> isometric = Q38 + Q39exertion = Q29 + Q31 + Q32
- e.  $\frac{Coworker Support}{Q41 + Q42 + Q44} + Q46$
- f.  $\frac{\text{Supervisory Support}}{\text{Q47} + \text{Q48} + \text{Q50} + \text{Q51}}$
- g. <u>Decision Latitude</u> (not used in this study) Skill Discretion + Decision Authority
- 2. <u>Sub-scales from Lorig's Self-Efficacy Scale (SES)</u>

These items are in Section 2 of the survey, on pages 8 through 11.

- a. <u>Self Efficacy Pain Subscale</u> page 8 (Q1 + Q2 + Q3 + Q4 + Q5) / 5 [Q: or, mean of Q1 through Q5?]
- b. <u>Self Efficacy Function Subscale</u> pages 9 - 10 (Q1 + Q2 + Q3 + Q4 + Q5 + Q6 + Q7 + Q8 + Q9) / 9
- c. <u>Self Efficacy Symptoms Subscale</u> pages 10 - 11 (Q1 + Q2 + Q3 + Q4 + Q5 + Q6) / 6

3. Health Assessment Questionnaire: Disability Scale (HAQ)

This scale is in Section 3 on page 11.

$$(Q1 + Q2 + Q3 + Q4 + Q5 + Q6 + Q7 + Q8) / 8$$

#### 4. Subscales from the SF-36 Health Survey

The SF-36 Health Survey is in Section 3, pages 12 through 15. Recoding and scoring follows the instructions in the SF-36 scoring manual (Ware et al., 1993).

a.	General Health		
	[Q1 + Q11], after re-coding.		
	Re-code Q1 as follows:	Excellent =	5.0
		Very Good =	4.4
		Good =	3.4
		Fair =	2.0
		Poor =	1.0

Reverse code responses to Q11b and Q11c, then sum Q11a, b, c, d to score Q11.

- b. <u>Physical Function</u> Sum Q3 a through j.
- c. <u>Role: Physical</u> Sum Q4 a through d.
- d. <u>Role: Emotional</u> Sum Q5 a through c.
- e. Social Function [Q6 + Q10], after re-coding.

Reverse code responses to Q6. (No change to responses to Q10).

f.  $\frac{\text{Bodily Pain}}{[Q7 + Q8], \text{ after re-coding.}}$ 

Re-code Q7 as follows:	None =	6.0
	Very mild =	5.4
	Mild =	4.2
	Moderate =	3.1
	Severe =	2.2
	Very Severe =	1.0
	Moderate = Severe = Very Severe =	3. 2. 1.

Re-code Q8 as follows:	Not at all =	6, if "none" selected in Q7
		5, if Q7 response $\neq$ "none"
	A little bit =	4
	Moderately =	3
	Quite a bit =	2
	Extremely =	1

- g. <u>Vitality</u> Sum [Q9a, e, g, i] after reverse coding Q9a and Q9e.
- h. <u>Mental Health</u> Sum [Q9b, c, d, f, h] after reverse coding Q9d and Q9h.

#### 5. Subscales from Zimet's Multidimensional Scale of Perceived Social Support (MSPSS)

These items are in Section 3, pages 15 to 16, Question 12.

- a. <u>Significant Other</u> [Sum Q12a, b, e, j]/4
- b. <u>Family</u> [Sum Q12c, d, h, k]/4
- c. <u>Friends</u> [Sum Q12f, g, i, 1]/4
- d. <u>Total Scale Score</u> (was not used in this study) [Sum Q12 a, b, ... 1]/12

#### Appendix 11 Cases that Reported 270 Hours of Work Last Week

Most represent full-time paid work plus some unpaid work, or full-time household work plus some paid work, and were proportional to work hours reported in their Occupational Questionnaires. Therefore, they were deemed reasonable reports from busy people. Some example descriptors are provided for asterisked cases.

case id	house	home	care	volunteer	studying	paid	all	total work
	work	maint	giving			work	unpaid	
		10 s			are up di i faith	MARSON (1990)	work	
K22	40.00	.00	8.00	.00	.00	40.00	48.00	88.00
K12	12.00	.00	2.00	4.00	.00	60.00	18.00	78.00
K17	50.00	1.00	.00	.00	3.00	18.00	54.00	72.00
K15	50.00	15.00	20.00	.00	.00	.00	85.00	85.00
NC1	38.00	6.00	14.00	10.00	25.00	.00	93.00	93.00
NC3	70.00	.00	16.00	2.00	.00	1.00	88.00	89.00
NC4	40.00	2.00	20.00	.00	.00	20.00	62.00	82.00
RE03	6.00	2.00	.00	4.00	32.00	35.00	44.00	79.00
RE36	5.00	2.00	14.00	.00	10.00	55.00	31.00	86.00
RE05	26.00	7.00	29.00	4.00	.00	20.00	66.00	86.00
RE45	50.00	4.00	50.00	2.00	.00	15.00	106.00	121.00
RE48	7.00	.00	60.00	.00	.00	25.00	67.00	92.00
RE39	40.00	7.00	50.00	.00	.00	.00	97.00	97.00
RE32	15.00	10.00	3.00	.00	.00	61.00	28.00	89.00
RE44	20.00	.00	65.00	2.00	7.00	21.00	94.00	* 115.00
RE34	20.00	.00	50.00	.00	.00	.00.	70.00	70.00
RE35	20.00	.00	70.00	3.00	.00	12.50	93.00	105.50
R91	20.00	5.00	20.00	.00	.00	60.00	45.00	105.00
R07	2.50	9.00	14.00	.00	.00	50.00	25.50	75.50
R60	60.00	4.00	7.00	.00	.00	.00	71.00	71.00
R17	30.00	.00	18.00	.00	.00	25.00	48.00	73.00
R26	20.00	2.00	.00	.00	.00	60.00	22.00	82.00
R51	40.00	4.00	10.00	2.00	.00	35.00	56.00	91.00
R63	108.00	.00	10.00	.00	.00	41.00	118.00	**159.00
R27	28.00	7.00	.00	3.00	3.00	40.00	41.00	81.00
R50	60.00	2.00	65.00	.00	.00	.00	127.00	***127.00
R44	17.00	1.50	30.00	15.00	20.00	9.00	83.50	92.50
R80	28.00	5.00	3.00	.00	.00	40.00	36.00	76.00
SH22	35.00	4.00	56.00	2.00	.00	.00	97.00	97.00
SH11	28.00	4.00	70.00	.00	.00	.00	102.00	102.00
RA22	12.00	8.00	20.00	.00	6.00	58.00	46.00	104.00
RA02	15.00	.00	55.00	3.00	.00	16.00	73.00	89.00
RA25	28.00	5.00	30.00	.00	.00	50.00	63.00	113.00
RA36	15.00	.00	50.00	.00	.00	35.00	65.00	100.00
RA14	10.00	10.00	.00	.00	.00	50.00	20.00	70.00
RA30	8.00	.00	.00	.00	.00	67.50	8.00	75.50
RA04	28.00	.00	.00	.00	.00	45.00	28.00	73.00
RA43	70.00	1.00	70.00	.00	.00	12.00	141.00	****153.00

"mother of very active 2-year old"

** "mom and night shift nurse, hardly slept"

*** "grandma caring for 2 year old grandchild and doing housework in 2 homes"

**** "mother of 4 children under 18"