

SPOUSE DEPRESSION AND DISEASE COURSE AMONG PERSONS WITH
RHEUMATOID ARTHRITIS

by

MARK MING-WAH LAM

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ABSTRACT

Objective. To examine the role of spouse mood in the disability and disease course of persons with Rheumatoid Arthritis (PWRA). *Methods.* 133 married PWRA completed questionnaires, including the Rheumatoid Arthritis Disease Activity Index and the Disabilities of the Arm, Shoulder and Hand, assessing PWRA arthritis disease activity and disability, respectively, at two time-points one-year apart. In addition, both PWRA and their spouses completed the Center for Epidemiological Studies Depression Scale, a standardized community measure of depression at both time-points. *Results.* Multiple regression analysis revealed spouse depressive symptoms at initial assessment to be predictive of follow-up PWRA disability and disease activity, even after controlling for initial levels of PWRA depression, disability, disease activity, age, number of years married, education, disease duration, and employment. More specifically, higher levels of spouse depression predicted worse disease course over a one-year period for PWRA, as indicated by higher reports of subsequent PWRA disability and disease activity. *Conclusion.* Our findings highlight the key role played by the spouse in PWRA disease course, and point to the importance of including the spouse in clinical interventions. Implications for theory, research, and treatment are discussed, with a focus on examining pathways through which spouse depressive symptoms may affect PWRA disease course and disability.

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CHAPTER 1

Introduction

Rheumatoid arthritis (RA) is an incurable autoimmune disease that affects approximately 1 in 100 Canadians. It is associated with a variety of distressing and debilitating symptoms including chronic pain, stiffness and inflammation of the joints, fatigue, and frequent mood changes. Among these, pain of variable duration and intensity is the most significant and problematic symptom for persons with RA. As a result of their disease and related distress, RA sufferers typically experience a wide range of daily stressors such as difficulties performing household chores, impaired ability to work or hold a job, difficulties engaging in leisure or social activities, and interpersonal tensions resulting from added burdens for friends and family members. Because there is no cure, RA treatment focuses on the alleviation of symptoms and an attempt to maintain functional status. Although early reports of pain (Turk & Melzack, 2001) and disability (Neugebauer & Katz, 2004) are initiated by biological factors, over time, psychosocial factors play a considerable role in the course and severity of RA.

Rheumatoid arthritis & mood

A key psychosocial factor consistently found to play a critical part in the course of RA is the mood of persons with RA (PWRA). For example, mood, independent of

stressful events, was found to be predictive of same-day pain, fatigue and stiffness in a sample of children with juvenile polyarticular arthritis, (Schanberg, Gil, Anthony, Yow & Rochon, 2005) and predictive of fatigue, stiffness and reduced activity in a sample of children with Juvenile Rheumatic Diseases (Schanberg et al. 2000). Interestingly, Fifield, Tennen, Reisine, and McQuillan (1998) suggested that the effects of mood can be long lasting, as a single episode of major depression has been found to predict subsequent levels of pain among PWRA. They found that PWRA with current depressive symptoms and a past episode of major depression reported more pain than others with only current depressive symptoms and no history of major depression. Along these same lines, PWRA with a history of two or more episodes of major depression were found to have higher levels of pain, both before and after stress induction, when compared to those with one or no prior episodes of major depression (Zautra et al., 2007). Even over the course of a day, PWRA mood has been found to predict changes in pain from morning to evening (Newth & DeLongis, 2004).

Close relationships & health

There is a great deal of evidence supporting the link between stress and physical and psychological well-being, and it is clear that social support is one of the most effective ways to mitigate the effect of stress on health and well-being. For most adults, an intimate relationship with a partner is one of the strongest sources of support in facing both major and minor life stress, and is the single most important social

relationship. Support from marital relationships holds the potential to offer a host of unique benefits. Spouses can be seen to provide multiple forms of support, including tangible and informational, and to play a particularly critical role in the provision of emotional support, especially during stressful events. In fact, support from other sources does not entirely compensate for a lack of spousal support (Coyne & DeLongis, 1986).

However, relationship difficulties are also the most frequent problems identified by adults seeking care from mental health providers (Revenson, Kayser, Bodenmann, 2005), and stress in close relationships has a greater impact on health and well-being than do other sources of stress (Bolger, DeLongis, Kessler, & Schilling, 1989). Given that nearly half of all marriages end in divorce, and that tension and conflict between spouses is present in most marriages at least some of the time (Bolger, Stadler, Paprocki, & DeLongis, in press), it seems clear that a spouse has the potential to be the greatest source of satisfaction but also the greatest source of conflict (Argyle & Furnham, 1983). This makes it very difficult to assess the overall benefits to health and well-being that marriage may provide.

Although married persons generally enjoy better health than do their unmarried counterparts, those who reported an inequitable, unsatisfying marriage showed higher levels of psychological distress than people who had never been married (Hagedoorn et al., 2006). Furthermore, marital conflict has been associated with poorer physical health and the onset of depressive symptoms, eating disorders, and alcohol abuse (Fincham, 2003). Marital conflict has also been shown to alter hormone levels (Kiecolt-Glaser et al., 1997), decrease immune responses (Glaser & Kiecolt-Glaser, 1994), and raise

blood pressure (Ewart, Taylor, Kraemer, & Agras, 1991). Over time, these negative marital interactions can lead to chronic health problems (for reviews, see Burman & Margolin, 1992; Kiecolt-Glaser & Newton, 2001).

A contextual model of stress and coping

Most marriages evidence support and conflict, with spouses enjoying the benefits of each other's support while also suffering the consequences of marital tension and conflict. We have found that day-to-day supportive and negative interactions with the spouse each make significant, independent contributions to the well-being of both members of the couple (DeLongis, Capreol, Holtzman, O'Brien, & Campbell, 2004) and that the impact of marital conflict on well-being appears to be greater than the beneficial effects of marital support on well-being, with the negative effects of marital tension and conflict amplified for those experiencing marital distress. Further, our findings suggest that those with low marital satisfaction are particularly vulnerable to mood disturbance on days when there is an absence of positive interactions with the spouse. These findings suggest that those high in marital satisfaction are better able to weather the natural ups and downs of married life. Even when sources of stress originate *outside* the context of a close relationship, much of the individual's coping is undertaken with the support of and in collaboration with an intimate partner. "How was your day?" is the prototypical first question asked as family members arrive home, and coping efforts may be planned or adjusted in light of the response of others.

Spouse mood & RA

Given the significant role of the spouse, it seems reasonable to consider mood as one pathway through which close others may impact PWRA disease course and disability. Studies on contagion of mood within close relationships have provided evidence for spousal similarity in depressive symptoms, such that one spouse's mood is linked to the other's (Joiner & Katz; 1999; Benazon & Coyne; 2000). For example, longitudinal research (Siegel, Bradley, Gallo, & Kasl, 2004) on more than 5000 married couples showed that spouses of those with higher baseline levels of depressive symptoms were themselves more likely to report subsequent depressive symptoms. Although there have been no studies examining such contagion effects among PWRA, taken together with findings on the role of PWRA mood in disease course, it is reasonable to expect that spouse mood is one path through which close relationships affect PWRA disease course. Consistent with this, Schwartz, Slater, Birchler, & Atkinson (1991) found a positive relationship between negative spouse mood and PWRA pain. However, their study was cross-sectional, so it remains unclear whether PWRA pain affects spouse mood, spouse mood impacts PWRA disease course, or both. This limitation of past research is highlighted by Ruiz, Matthews, Schulz, and Scheier's recent assertion (2006) that they could find no prospective studies examining spousal characteristics as predictors of PWRAs' health and well-being. They argued that employing prospective study designs would strengthen future research, allowing for the examination of causal issues. A further limitation of the vast majority of research on the ways in which the spouse may impact PWRA disease course and well-being is that it has relied primarily

on PWRA's perception of the spouse. With the notable exception of Sterba et al. (2008) examining couple illness perception congruence on psychological adjustment in women with RA,, there is a dearth of research that actually involves the spouse, rather than relying solely on PWRA perceptions of spouse mood and behaviour. Recently, Keefe and Porter (2007) argued for simultaneously collecting data from both PWRA and spouse, painting a more complete picture of the important interactions at play within the dyad.

Current study

Following these recommendations, our study examined the relationship between spouse depression and disease course among those living with RA. A prospective examination of the role of spouse mood in PWRA disability and pain was undertaken, with PWRA and their spouses separately completing initial and one-year follow-up questionnaires that included assessment of depression and health status. In addition, PWRA also completed a set of standardized measures of RA-related disease activity, pain, and functional ability. The effects of spouse mood on PWRA disease activity and disability were examined, and it was hypothesized that increased spousal depression would be predictive of subsequent PWRA disease activity and disability, even after controlling for initial PWRA depression and disease activity.

CHAPTER 2

Participants and methods

Participants were recruited as part of a larger study investigating concordance of PWRA and partner perceptions of PWRA pain, fatigue and disability (Lehman et al., 2006). Only those procedures and measures used in the current study are discussed here. Participants were eligible if they were diagnosed with RA by a physician, and the time since diagnosis exceeded six months. PWRA and their partners were at least 19 years of age and cohabiting for a minimum of one year. Partner status was defined as being married or maintaining a common-law relationship. Exclusion criteria included an inability of either partner to comprehend written English. Participants were recruited via physician contacts and advertisements, as well as via PWRA advocacy groups and community recruitment postings. Interested persons contacted a researcher requesting questionnaires. Members of the couple were mailed two sets of questionnaires, which they each completed independently. Participants' names were entered into lottery draws for prizes valued between \$50 and \$500. Participants were followed up via telephone if questionnaires had not been received within 14 days after they were mailed to them. Follow-up phone calls were also made if questionnaires were incomplete in order to obtain missing information. Research was carried out in compliance with the Helsinki Declaration and approval was granted by the University of British Columbia ethics board.

Of the 275 eligible couples that were sent initial questionnaires, 226 (82%) returned both PWRA and partner questionnaires within a week of each other. Of those, four couples were excluded due to missing data; final N = 222. Of the 226 participants surveyed in the initial questionnaire, 211 consented to being contacted with the follow-up questionnaires. Two persons did not participate in the follow-up because their spouses had died, and eleven couples could not be contacted as they had moved. 135 of these 211 questionnaires were returned by at least the PWRA. Of those returned two were excluded due to excessive missing data. When compared using independent sample t-tests, those who completed both initial and follow-up questionnaires did not differ significantly (α level = .05) on study variables or demographics, with the exception of ethnicity (all seven Chinese PWRA completed initial questionnaires only) and employment status (more PWRA who completed initial questionnaires only were employed fulltime and less were retired).

The final sample consisted of 133 couples in which both PWRA and partner had completed the initial questionnaire and at least the PWRA had completed the follow-up questionnaire. PWRA were predominantly female (72.9%), Caucasian (96.2%), and ranged in age from 29 to 86 (mean = 62.35, SD = 12.65). Spouses were mostly male (71.4%), Caucasian (95.5%) and ranged in age from 28 to 86 (mean = 63.26, SD = 12.70). Initially, participants had been married (94%) or cohabiting (6%) with their partner for an average of 33.4 years (SD = 15.71), ranging from 1 to 62 years. At follow-up, rates of marriage decreased to 92.7% due to two incidences of death and one of divorce. On average, PWRA were diagnosed 12.8 prior (SD = 11.3), with durations

ranging from 1 to 44 years. Most participants (85%) and spouses (87.2%) had completed high school. At the time of the initial questionnaire, 28.6% of participants were employed outside the home (60.5% full-time), with the rest either homemakers (14.3%), retired (41.4%), or on leave due to disability (13.5%). 46.6% of spouses were employed (83.9% full-time), with the remainder homemakers (5.3%), retired (44.4%), or on disability (0.8%).

Measures

RA disease activity.

Symptoms of RA, including pain, swelling, tenderness, stiffness, and fatigue were measured using the Rheumatoid Arthritis Disease Activity Index (RADAI; Stucki, Liang, Stucki, Bruhlman, & Michael, 1995). Participants indicated symptom severity for the present day by using a numerical rating scale ranging from 0 (no pain) to 10 (very severe pain). These ratings were averaged and summed together with ratings of joint pain producing a score that indicated worse outcomes for higher scores. Participants indicated the specific joints in which they felt pain that day by marking the severity of the pain in each joint (mild, moderate, severe). Cronbach alpha coefficients were equivalent for both initial and follow-up measurements ($\alpha = .89$). The RADAI has strong convergent validity, correlating with clinical assessments and health questionnaires (Fransen, Langenegger, Michael, Stucki, 2000).

Physical limitations.

Disabilities of the Arm, Shoulder, and Hand (DASH; Hudak et al., 1996) assessed multi-dimensional aspects of physical limitations, including pain, weakness, tingling and stiffness. The measure assesses the range of physical challenges people with RA experience. Responses ranged from 1 (No difficulty) to 5 (Unable) and scores were calculated by subtracting one from the mean of all 30 items then multiplying by 25. Higher scores indicate greater disability. Reliability was high at both time-points (α 's = .97); the DASH has known validity and reliability (Beaton et al, 2001).

Depressive symptoms.

Depressive symptoms were measured for both PWRA and partners using the Center for Epidemiological Studies Depression Scale (CES-D; Radloff, 1977). The CES-D is a widely used measure of depression specifically for community populations. Participants were asked to indicate their responses to each item in terms of the past week on a scale ranging from 0 (rarely or none of the time) to 3 (most or all of the time). Four positive items were reverse coded and then summed with the remaining 16 items. Cronbach alpha coefficients were calculated for both PWRA ($\alpha = .89$) and spouses ($\alpha = .87$). The CES-D demonstrates good internal consistency across diverse population subgroups and has good test-retest reliability (Radloff, 1977; Aneshensel, Clark, & Frerichs, 1983; Fava, 1983; Roberts, 1980; Ross & Mirowsky, 1984).

Results

Univariate analyses

Distributional properties of study variables were assessed for departures from normality, and potential outliers were examined to determine the degree of influence exhibited. Initially, PWRA reported an average level of RA disease activity and disabilities of the arms, shoulders and hands of 4.03 (SD = 2.30) and 37.18 (SD = 21.00) respectively (Table 1). At follow-up, levels of disease activity and disabilities of the arms, shoulders, and hands of PWRA had decreased significantly to 3.62 (SD = 2.17) and 35.63 (SD = 20.95) respectively. Initially, the mean CES-D scores for PWRA were 13.78 (SD = 9.83), while mean scores for partners were 9.74 (SD = 8.54). At follow-up, mean CES-D scores for PWRA and their partners were 11.69 (SD = 9.04) and 8.46 (SD = 8.03) respectively. Paired t-tests comparing initial and follow-up levels of study variables revealed higher initial levels of PWRA disease activity and depressive symptoms, $t(130) = 2.07, p < .05$ and $t(129) = 2.78, p < .05$. Similarly, spouses evidenced higher initial levels of depressive symptoms than at follow-up, $t(120) = 2.18, p < .05$. Initial and follow-up levels for PWRA DASH scores were not found to be significantly different, $t(129) = 1.04, p > .10$. Paired t-tests also indicated that CES-D scores were significantly higher for PWRA when compared to their spouses, both initially, $t(131) = 4.03, p < .001$ and at follow-up, $t(119) = 3.24, p < .01$. Finally, no gender differences were found in initial or follow-up levels on the CES-D, $p > .10$.

Bivariate analyses

Not surprisingly, scores on initial measures for each of the study variables (Table 1) were highly and significantly positively correlated with scores on the same measures at follow-up (DASH $r = .78, p < .01$; RADAI $r = .56, p < .01$). As expected outcome measures of disability and RA disease activity were also highly and significantly inter-correlated, both initially ($r = .67, p < .01$) and at follow-up ($r = .64, p = .01$). In line with previous research (Dickens, McGowan, Clark-Carter & Creed, 2002), PWRA CES-D scores at time 1 were positively and significantly related to both initial ($r = .42, p < .01$) and follow-up ($r = .28, p < .01$) measures of disability and initial levels of RA disease activity ($r = .46, p < .01$). Finally, initial spouse CES-D scores were directly related to both PWRA outcome variables initially (DASH $r = .19, p < .05$; RADAI $r = .18, p < .05$) and at follow-up (DASH $r = .28, p < .01$; RADAI $r = .26, p < .01$), as well as PWRA CES-D scores at both time points (initial; $r = .23, p < .01$; follow-up; $r = .31, p < .01$).

Hierarchical multiple regression models.

Spouse Depression and Disabilities of the Arms, Shoulders and Hands. Hierarchical multiple regression analysis was conducted, predicting the physical function of the PWRA's upper extremities at follow-up from PWRA gender, and initial levels of partner depressive symptoms, PWRA depressive symptoms, PWRA physical functioning, age, years married, education, disease duration, and employment (Table 2). Together these predictors accounted for a significant portion of variance in follow-up levels of PWRA physical functioning, $R^2 = 0.64, F(7,121) = 30.19, p < .001$, with an adjusted $R^2 = 0.62$. The addition of initial levels of spouse depressive symptoms in the second step

significantly increased the proportion of explained variance, $R^2\Delta = 0.02$, $p < .001$. As predicted, above and beyond gender and initial levels of PWRA depressive symptoms and physical functioning, initial levels of spouse depressive symptoms made a unique and significant contribution to the prediction of the PWRA's physical functioning at follow-up, $\beta = .16$, 95% CI [.05, .27], $t(121) = 2.91$, $p < .01$. The interaction term genderXspouse depressive symptoms was added to the model. However, gender did not moderate the relationship between spouse depressive symptoms and PWRA disability, $p > .10$. Follow-up mediational analyses (Baron & Kenny, 1986) examining the possibility that the path through which spouse depressive symptoms impacted PWRA disability and disease activity was via changes in PWRA depressive symptoms were non-significant (figure 1).

Spouse Depression and RA Disease Activity. Hierarchical multiple regression analysis was conducted predicting RA disease activity at follow-up from PWRA gender, and initial levels of PWRA disease activity, PWRA and partner depressive symptoms, age, years married, education, disease duration, and employment (Table 2). Together these predictors accounted for a significant portion of variance in follow-up levels of PWRA disease activity, $R^2 = 0.37$, $F(7,122) = 10.06$, $p < .001$, with an adjusted $R^2 = 0.33$. The addition of initial levels of spouse depressive symptoms in the second step significantly increased the proportion of explained variance $R^2\Delta = 0.03$, $p < .001$. Initial levels of spouse depressive symptoms made a unique and significant contribution to the prediction of the PWRA's disease activity at follow-up, controlling for gender and initial levels of PWRA depressive symptoms and disease activity, $\beta = .18$, 95% CI [.04, .33], t

(122) = 2.39, $p < .05$. The interaction term genderXspouse depressive symptoms was added to the model; however gender did not moderate the relationship between spouse depressive symptoms and PWRA disease activity, $p > .10$. As mentioned above, initial PWRA depressive symptoms were directly and positively related to both initial and follow-up measures of disease activity at the bivariate level. At the multivariate level, decreases in initial PWRA depressive symptoms were predictive of increases in follow-up levels of PWRA disease activity, holding gender, initial spouse depressive symptoms, initial PWRA disease activity, age, years married, employment, education and disease duration constant, $\beta = -.21$, $t(121) = -2.64$, $p < .01$. Multicollinearity between initial PWRA depressive symptoms and initial PWRA disease activity may account for the change observed in the direction of the beta from positive to negative for PWRA depressive symptoms when comparing the direction of the relationship found at the bivariate to the multivariate level. This may be a function of negative suppression as such suppression is more frequent under conditions of high correlation between predictors (Tzelgov & Henik, 1991). Tzelgov & Henik (1991) note that high intercorrelations among predictors are not necessarily indicative of unstable regression coefficients. Given this, it would be premature to dismiss the surprising relationship we have found between PWRA depression and PWRA health outcomes out of hand, yet replication is called for prior to drawing the conclusion that the association is veridical.

Although PWRA depressive symptoms were included in the present models as a control variable only, it should be noted that Paulhus, Robins, Trzesniewski, and Tracy (2004) have argued for relying on the bivariate coefficient for interpretation in such

situations. Finally, as with our findings reported above using DASH scores as indicators of PWRA disability, we conducted follow-up mediational analyses (Baron & Kenny, 1986). We examined the possibility that the path through which spouse depressive symptoms impacted PWRA disability was via changes in PWRA depressive symptoms, and these mediational tests were again non-significant (figure 2).

Table 1. Descriptives and bivariate correlations between Disabilities of Arm, Shoulder and Hand (DASH), RA Disease Activity (RADAI), and depression

	1.	2.	3.	4.	5.	6.	7.	8.
1. PWRA DASH, Time 1	-							
2. PWRA DASH, Time 2¥	.78**	-						
3. PWRA RADAI, Time 1	.67**	.52**	-					
4. PWRA RADAI, Time 2§	.44**	.64**	.56**	-				
5. PWRA Depression Time 1	.42**	.28**	.46**	.12	-			
6. Spouse Depression Time 1†	.19*	.28**	.18*	.26**	.23**	-		
7. PWRA Depression Time 2¥	.24**	.30**	.28**	.22*	.69**	.31**	-	
8. Spouse Depression Time 2‡	.18*	.22*	.16	.18*	.27**	.72**	.29*	-
Mean	37.18	35.63	4.03	3.62	13.78	9.74	11.69	8.46
Standard Deviation	21.00	20.95	2.30	2.17	9.83	8.54	9.04	8.03

*p<.05, **p<.01

†N=132

§ N=131

¥N= 130

‡ N=121

Table 2. Hierarchical linear regression predicting Disabilities of the Arm, Shoulder, and Hand (DASH), and RA Disease Activity (RADAI)

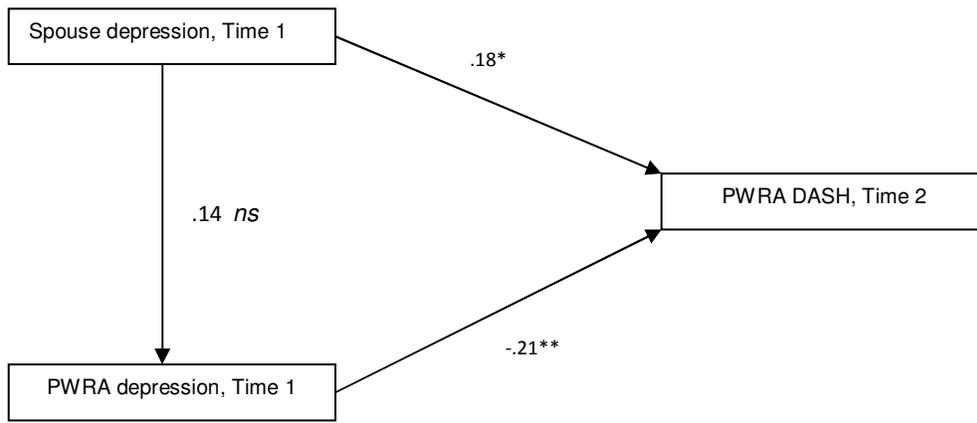
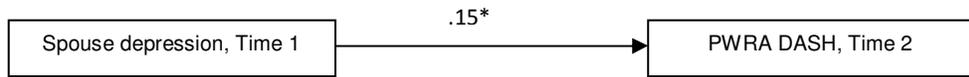
	PWRA DASH, Time 2			PWRA RADAI, Time 2		
	B	SE	β	b	SE	β
Step 1						
PWRA DASH, Time 1	0.74	0.07	0.75***			
PWRA RADAI, Time 1				0.62	0.08	0.65***
Gender	-7.15	2.99	-0.15**	-0.53	0.38	-0.11
PWRA CES-D, Time 1	-0.11	0.13	-.05	-0.04	0.02	-0.18*
R ² Δ	0.64***			0.37***		
Step 2						
PWRA DASH, Time 1	0.72	0.07	0.73***			
PWRA RADAI, Time 1				0.60	0.08	0.64***
gender	-6.58	2.93	-0.14**	-0.47	0.39	-0.10
PWRA CES-D, Time 1	-0.17	0.13	-0.08	-0.05	0.02	-0.21**
Spouse CES-D, Time 1	0.40	0.14	0.16**	0.05	0.02	0.18*
R ² Δ	0.02**			0.03***		

*p<.05, **p<.01, ***p<.001

† female=1, male=2

Age, years married, employment, disease duration, and education, $p > .10$.

Figure 1. Mediation test of PWRA depression on relationship between spouse depression and PWRA disability

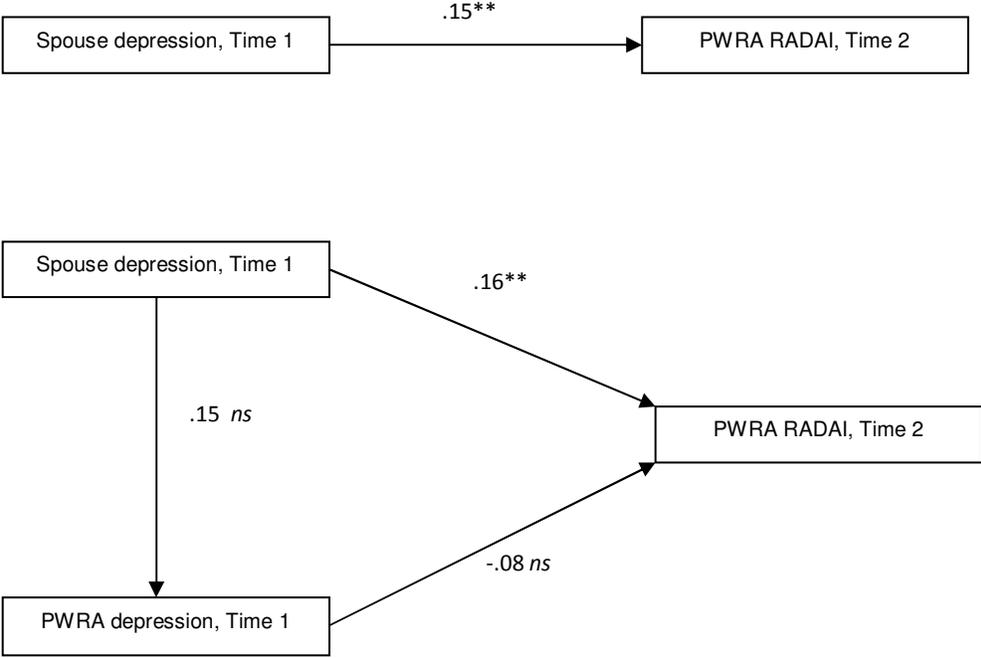


ns = non-significant

* $p < 0.05$

** $p < 0.01$

Figure 2. Mediation test of PWRA depression on relationship between spouse depression and PWRA disease activity



ns = non-significant
*** p < 0.01*

CHAPTER 3

Discussion

The central findings from the current study suggest that a) spouse depressive symptoms play a key role in PWRA disease course, and importantly, b) this effect holds even after controlling for PWRA depression, disability, disease activity, age, number of years married, education, disease duration, and employment. More specifically, higher levels of spouse depression predicted worse disease course over a one-year period for PWRA, as indicated by reports of higher subsequent PWRA disability and disease activity.

There is a large literature indicating a role of social relationships in health (Keefe & Porter, 2007), and in particular a key role for close relationships. However, the pathways through which close relationships exert their influence on health and well-being are unclear. Although a positive perception of the spouse is associated with health benefits (Coyne & DeLongis, 1986), the possibility exists that these positive perceptions lie in the eye of the beholder, and have little to do with the spouse him or herself. Because we obtained reports from both members of the couple, rather than relying solely on ill persons' perceptions of their partners, our findings provide support for a role for the spouse, and not just perceptions of the spouse, specifically via spouse depressive symptoms, in disease outcomes.

There are three theoretical models that should be considered in interpreting the inter-relationship in mood between members of a couple. First, drawing on a model of

mood contagion (Joiner & Katz, 1999), it is possible that spouses' depression could "infect" PWRA, increasing their own depressive symptoms and thus impacting RA disease course. In their review of the literature on social contagion of depressive symptoms and mood, Joiner and Katz (1999) posit key behavioural and cognitive explanations that are most likely relevant in the context of established close relationships. Cognitive theories of depression hypothesize that individuals who tend to explain and perceive the world negatively are vulnerable to depression when they encounter negative life events. Joiner and Katz (1999) suggest the possibility that the spouse's negative attributions about his or her partner's marital distress, depression, or both serves as a vulnerability factor to his or her own depression. A behavioural explanation based on operant conditioning principles suggests that depressive symptoms may be transmitted to the spouse because of their depressed partner's inability to provide response-contingent positive reinforcement, leading to a depleted interpersonal environment lacking in support.

Second, depression in both partners may co-exist due to assortative mating. Evidence suggests that depressed individuals may select a similarly depressed mate (Matthews & Reus, 2001; Maes et al., 1998). Despite these possibilities, by controlling for initial levels of PWRA depression, and by ruling out PWRA depression as a potential mediator of the relationship between spouse depressive symptoms and PWRA outcomes, our findings suggest that spouse depression makes a unique and direct contribution to the prediction of PWRA disease course and disability that is not entirely through its effect on PWRA depression. Although our findings are consistent with these

models in that spouse depressive symptoms and PWRA depressive symptoms were significantly associated both at the same point in time and across time, our findings suggest that the relationship of spouse depressive symptoms with PWRA health outcomes is not due solely to either assortative mating or mood contagion. Our findings indicate that above and beyond the inter-relationship of depressive symptoms between spouses, spouse depressive symptoms are playing a role in PWRA disease course.

A third model for understanding the association between spouse and PWRA mood, and perhaps most useful, is a caregiving model in which chronic disease impacts the well-being of both an ill person and his or her caregiving partner. Several studies have found that spouses caring for persons living with chronic pain have increased rates of depressive symptoms (Schwartz et al., 1991; Romano & Schmalzing, 2001). For example, in an examination of the ways in which arthritis affects the spouse, verbal and non-verbal expressions of pain from women with osteoarthritis predicted poorer psychological well-being in their caregiving husbands (Stephens, Martire, Cremeans-Smith, Druley, & Wojno, 2006). This large literature on caregiving for persons with chronic disease focuses on the impact of the disease on the caregiver. However, the question remains as to the path through which spouse-caregiver depressive symptoms might impact PWRA health outcomes.

Spousal provision of support may be one key path through which spouse depression impacts PWRA disease course and disability. When spouses are depressed they may be less likely to provide satisfactory support to PWRA (Benazon & Coyne, 2000). Satisfaction with support from the spouse has been found to affect

PWRA well-being by impacting the type of coping utilized by PWRA (Manne & Zautra, 1989, Holtzman, Newth & DeLongis, 2004), with those PWRA reporting satisfaction with social support tending to put more effort into their coping (Holtzman et al., 2004) and to engage in coping that is more adaptive (Manne & Zautra, 1989). In addition, Holtzman, et al., (2004) found that satisfaction with spouse support among PWRA enhanced the efficacy of coping in reducing RA pain. Further, Holtzman and DeLongis (2007) found that PWRA satisfaction with spouse support tended to disrupt the vicious cycle between pain and catastrophizing, which often plagues those suffering from chronic pain (Sullivan et al., 2001). In a similar vein, spouse criticism may be a path through which spouse depression impacts PWRA disability and disease course. Coyne and Benazon (2001) have argued that depressed persons have a tendency to be critical and hostile towards their spouses. Manne and Zautra (1989) found PWRA with highly critical spouses were more likely to display maladaptive coping strategies and exhibit poorer psychological adjustment. These researchers did not examine the effect of spouse criticism on PWRA disease outcomes. However, taken together with other studies showing a link between PWRA coping and disease course (Newth & DeLongis, 2004; Holtzman & DeLongis, 2007; Keefe, Abernathy, Campbell, 2005), it seems reasonable to posit that a cascade of events may occur in which depressed spouses may criticize PWRA, who in turn then cope poorly with their pain and disability. This in turn, might result in a more negative disease course. Research is needed that assesses this full set of factors in both members of the dyad.

Generalizability of our findings is limited by the homogeneity of our sample, which consists primarily of well educated, married, heterosexual, Canadian couples of European descent. In addition, our sample is composed disproportionately of couples in which the wife has RA, reflecting gender differences in the prevalence of RA in the general population. Given that RA disproportionately affects women, the role of patient and the role of wife tend to be confounded in couples research on RA (Revenson, Abraído-Lanza, Majerovitz, & Jordan, 2005). Gender differences exist in both stress processes, (Zwicker & DeLongis, in press, Jordan & Revenson, 1999) and depression (Hagedoorn, Sanderman, Bolks, Tuinstra, & Coyne, 2008). Further, women are more likely to serve in the caregiver role (DeLongis & O'Brien, 1990) and female caregivers tend to report more health problems (Vitaliano, Zhang, & Scanlan, 2003) and greater distress (Lutzky & Knight, 1994) than do male caregivers. However, we found no gender differences in depression or in the effects of spousal depression on PWRA outcomes. It is possible that we simply did not have the power to detect gender differences in these processes, and future research with a larger N, particularly with larger numbers of husbands with RA, may detect differences in these processes. Similarly, due to the homogeneity of our sample, we were unable to examine how cultural or other life style factors might influence the processes we have described here. Yet, there is good reason to expect such factors make a difference in dyadic processes (McGoldrick, Giordano, & Garcia-Preto, 2005).

Implications for treatment

Although our findings suggest a key role for the spouse in PWRA disease course, whether these findings can be translated into effective clinical interventions has yet to be seen (Coyne, Stefanek, & Palmer, 2007). Our findings do however highlight the importance of looking beyond the individual as the treatment unit, suggesting the utility of seeing the dyad as the treatment unit instead. Martire, Schultz, Keefe, Rudy and Starz (2007) suggest couple interventions could reduce stress and critical attitudes in spouses, thus providing indirect benefits to their ill partners (Lanza & Revenson, 1993). Interventions that target only PWRA depression and strategies for coping with the disease may not be sufficient in the presence of a depressed spouse. Whether depressed spouses are unable or unwilling to provide much needed support to the PWRA, or whether their depressed mood affects PWRA outcomes in some other way, is yet to be determined. However, the mood and mental health of the marital partner or other key members of the family may be critically important to consider in developing more effective, evidence-based treatments.

BIBLIOGRAPHY

- Aneshensel, C. S., Clark, V. A., & Frerichs, R.R. (1983). Race, ethnicity, and depression: A confirmatory analysis. *Journal of Personality and Social Psychology*, 44, 385-398.
- Argyle, M., & Furnham, A. (1983). Sources of satisfaction and conflict in long-term relationships. *Journal of Marriage & the Family*, 45 (3), 481 – 493.
- Baron, R.M. & Kenny, D.A. (1986). The moderator-mediator variable distinction in social psychological research: Conceptual, strategic, and statistical considerations. *Journal of Personality and Social Psychology*, 51, 1173-1182.
- Beaton, D. E., Katz, J. N., Fossel, A. H., Wright, J. G., Tarasuk, V., & Bombardier, C. (2001). Measuring the whole or the parts? Validity, reliability, and responsiveness of the disabilities of the arm, shoulder and hand outcome measure in different regions of the upper extremity. *Journal of Hand Therapy*, 14, 128-146.
- Benazon, N. R. & Coyne, J. C. (2000). Living with a depressed spouse. *Journal of Family Psychology*, 14, 71-79.
- Bolger, N., DeLongis, A., Kessler, R. C., & Schilling, E. A. (1989). Effects of daily stress on negative mood. *Journal of Personality and Social Psychology*, 808-818.
- Bolger, N., Stadler, G., Paprocki, C. & DeLongis, A. (in press). Grounding social psychology in behavior in daily life: The case of conflict and distress in couples. In C. Agnew, D.E. Carlston, W.G. Graziano, & J.R. Kelly (Eds.), *Then a miracle occurs: Focusing on behavior in social psychological theory and research*. New York, NY: Oxford University Press.
- Burman, B., & Margolin, G. (1992). Analysis of the association between marital relationships and health problems: An interactional perspective. *Psychological Bulletin*, 112(1), 39-63.
- Coyne, J. C. & Benazon, N. R. (2001). Not agent blue: Effects of marital functioning on depression and implications for treatment. In: S.R.H. Beach (Ed.), *Marital and family processes in depression: A scientific foundation for clinical practice* (p. 25-43). Washington DC: American Psychological Association.

- Coyne, J. C. & DeLongis, A. (1986). Going beyond social support: The role of social relationships in adaptation. *Journal of Consulting Clinical Psychology*, 1986; 54: 454-60.
- Coyne, J.C., Stefanek, M., & Palmer, S.C. (2007). Psychotherapy and survival in cancer: The conflict between hope and evidence. *Psychological Bulletin*, 133, 367-394.
- DeLongis, A., Capreol, M., Holtzman, S., O'Brien, T., & Campbell, J. (2004). Social Support and Social Strain Among Husbands and Wives: A Multilevel Analysis. *Journal of Family Psychology*, 18(3), 470-479.
- DeLongis, A. & O'Brien, T.B. (1990). An interpersonal framework for stress and coping: An application to the families of Alzheimer's patients. In M.A.P. Stephens, J.H. Crowther, S.E. Hobfoll, & D.L. Tennenbaum (Eds.), *Stress and coping in later life families* (p.221-229). Washington, DC: Hemisphere Publishers.
- Dickens, C., McGowan, L., Clark-Carter, D., & Creed, F. (2002). Depression in rheumatoid arthritis: A systematic review of the literature with meta-analysis. *Psychosomatic Medicine*, 64, 52–60.
- Ewart, C.K., Taylor, C.B., Kraemer, H.C., & Agras, W.S. (1991). High blood pressure and marital discord: Not being nasty matters more than being nice. *Health Psychology*, 10(3), 155-163.
- Fava, G.A. (1983). Assessing depressive symptoms across cultures: Italian validation of the CES-D self rating scale. *Journal of Clinical Psychology*, 39, 249-251.
- Fifield, J., Tennen, H., Reisine, S., & McQuillan, J. (1998). Depression and the long-term risk of pain, fatigue, and disability in patients with rheumatoid arthritis. *Arthritis & Rheumatism*, 41, 1851-1857.
- Fincham, F.D. (2003). Marital conflict: Correlates, structure, and context. *Current Directions in Psychological Science*, 12(1), 23-27.
- Fransen, J., Langenegger, T., Michel, B.A., & Stucki, G. (2000). Feasibility and validity of the RADAI, a self-administered rheumatoid arthritis disease activity index. *Rheumatology*, 39, 321-327.
- Glaser, R., & Kiecolt-Glaser, J.K. (Eds.). (1994). *Handbook of human stress and immunity*. San Diego, CA: Academic Press.

- Hagedoorn, M., Sanderman, R., Bolks, H.N., Tuinstra, J., & Coyne, J.C. (2007). Distress in couples coping with cancer: A meta-analysis and critical review of role and gender effects. *Psychological Bulletin*, 134, 1-30.
- Hagedoorn, M., Van Yperen, N. W., Coyne, J. C., van Jaarsveld, E., Ranchor, A.V., van Sonderen, E., Sanderman, R. (2006). Marital status and equity within the marriage: Does marriage protect older people from psychological distress? *Psychology and Aging*, 21, 611-620.
- Holtzman, S. & DeLongis, A. (2007). One day at a time: The impact of daily spouse support on pain, negative affect and catastrophizing among individuals with rheumatoid arthritis. *Pain*, 131, 202-213.
- Holtzman, S., Newth, S., & DeLongis, A. (2004). The role of social support in coping with daily pain among patients with rheumatoid arthritis. *Journal of Health Psychology*, 9, 677–695.
- Hudak, P.L., Amadio, P.C., Bombardier, C., Boland, A., Fischer, T., Flatow, E.L., et al. (1996). Development of an upper extremity outcome measure: The DASH (Disabilities of the Arm, Shoulder, and Head). *American Journal of Industrial Medicine*, 29, 602-608.
- Joiner, T.E. & Katz, J. (1999). Contagion of depressive symptoms and mood: Meta-analytic review and explanations from cognitive, behavioral, and interpersonal viewpoints. *Clinical Psychology: Science and Practice*, 6, 149-164.
- Jordan, C. & Revenson, T.A. (1999). Gender differences in coping with infertility: A meta-analysis. *Journal of Behavioral Medicine*, 22, 341-358.
- Keefe, F.J., Abernethy, A.P., & Campbell, L.C. (2005). Psychological approaches to understanding and treating disease-related pain. *Annual Review of Psychology*, 56, 601–630.
- Keefe, F.J. & Porter L. (2007). Pain catastrophizing in the context of satisfaction with spousal responses: New perspectives and new opportunities. *Pain*, 131, 1-2.
- Kiecolt-Glaser, J.K., & Newton, T.L. (2001). Marriage and health: His and hers. *Psychological Bulletin*, 127(4), 472-503.
- Kiecolt-Glaser, J.K., Glaser, R., Cacioppo, J.T., MacCallum, R.C., Snyder-Smith, M., Kim, C., et al. (1997). Marital conflict in older adults: Endocrinological and immunological correlates. *Psychosomatic Medicine*, 59(4), 339-349.

- Lanza, A.F. & Revenson, T.A. (1993). Social support interventions for rheumatoid arthritis patients: The cart before the horse. *Health Education Quarterly*, 20, 97-117.
- Lehman, A.J., Pratt, D., DeLongis, A., Collins, J., Shojania, K., Koehler, B., et al. Do spouses know how much fatigue and pain their partners with rheumatoid arthritis experience? Implications for social support. *Arthritis & Rheumatism*, 54, S303-304.
- Lutzky, S.M. & Knight, B.G. (1994). Explaining gender differences in caregiver distress: The roles of emotional attentiveness and coping styles. *Psychology and Aging*, 9, 513-519.
- Maes, H.H.M., Neale, M.C., Kendler, K.S., Hewitt, J.K., Silberg, J.L., Foley, D.L., et al. Assortative mating for major psychiatric diagnoses in two population-based samples. *Psychological Medicine*, 28, 1389-1401.
- Manne, S.L. & Zautra, A.J. (1989). Spouse criticism and support: Their association with coping and psychological adjustment among women with rheumatoid arthritis. *Journal of Personality and Social Psychology*, 56, 608-617.
- Martire, L.M., Schultz, R., Keefe, F.J., Rudy, T.E., & Starz, T.W. (2007). Couple-oriented education and support intervention: Effects on individuals with osteoarthritis and their spouses. *Rehabilitation Psychology*, 52, 121-132.
- Mathews, C.A. & Reus, V.I. (2001). Assortative mating in the affective disorders: A systematic review and meta-analysis. *Comprehensive Psychiatry*, 42, 257-262.
- McGoldrick, M., Giordano, J., & Garcia-Preto, N. (Eds.). (2005). *Ethnicity & family therapy*. New York: Guilford Press.
- Neugebauer, A. & Katz, P.P. (2004). Impact of social support on valued activity disability and depressive symptoms in patients with rheumatoid arthritis. *Arthritis Care & Research*, 51, 586-592.
- Newth, S. & DeLongis, A. (2004). Individual differences, mood, and coping with chronic pain in Rheumatoid arthritis: A daily process analysis. *Psychology & Health*, 19, 283-305.
- Paulhus, D., Robins, R.W., Trzesniewski, K.H., & Tracy, J. (2004). Two replicable suppressor situations in personality research. *Multivariate Behavioral Research*, 39: 301-26.

- Radloff, L.S. (1977). The CES-D Scale: A self-reported depression scale for research in the general population. *Applied Psychological Measurement*, 1, 385–401.
- Revenson, T.A., Abraído-Lanza, A.F., Majerovitz, S.D., & Jordan, C. (2005). Couples coping with chronic illness: What's gender got to do with it? In: T.A. Revenson, K. Kayser, & G. Bodenmann (Eds.), *Couples coping with stress: Emerging perspectives on dyadic coping* (p.137-156). Washington DC: American Psychological Association.
- Revenson, T.A., Kayser, K., & Bodenmann, G. (2005). *Couples coping with stress: Emerging perspectives on dyadic coping*. Washington, DC: American Psychological Association.
- Roberts, R.E. (1980). Reliability of the CES-D scale in different ethnic contexts. *Psychiatry Research*, 2, 125-34.
- Romano, J.M. & Schmalzing, K.B. (2001). Assessment of couples and families with chronic pain. In D. Turk & R. Melzack (Eds.), *Handbook of pain assessment (2nd ed)*, (pp. 346-361). New York: Guilford Press.
- Ross, C.E. & Mirowsky, J. Components of depressed mood in married men and women: The Center for Epidemiologic Studies depression scale. *American Journal of Epidemiology*, 119, 997-1004.
- Ruiz, J.M., Matthews, K.A., Schulz, R., & Scheier, M.F. (2006). Does who you marry matter for your health? Influence of patients' and spouses' personality on their partners' psychological well-being following coronary artery bypass surgery. *Journal of Personality and Social Psychology*, 91, 255–267.
- Schanberg, L.E., Sandstrom, M.J., Starr, K., Gil, K.M., Lefebvre, J.C., Keefe, F.J., et al. The relationship of daily mood and stressful events to symptoms in juvenile rheumatic disease. *Arthritis Care & Research*, 13, 33-41.
- Schanberg, L.E., Gil, K.M., Anthony, K.K., Yow, E., & Rochon, J. (2005). Pain, stiffness, and fatigue in juvenile polyarticular arthritis: Contemporaneous stressful events and mood as predictors. *Arthritis & Rheumatism*, 52, 1196-1204.
- Schwartz, L., Slater, M.A., Birchler, G.R., & Atkinson, J.H. (1991). Depression in spouses of chronic pain patients: The role of patient pain and anger, and marital satisfaction. *Pain*, 44, 61-67.

- Siegel, M.J., Bradley, E.H., Gallo, W.T., & Kasl S.V. (2004). The effect of spousal mental and physical health on husbands' and wives' depressive symptoms, among older adults: Longitudinal evidence from the health and retirement survey. *Journal of Aging and Health*, 16, 398-425.
- Stephens, M.A.P., Martire, L.M., Cremeans-Smith, J.K., Druley, J.A., & Wojno, W.C. (2006). Older women with osteoarthritis and their caregiving husbands: Effects of pain and pain expression on husbands' well-being and support. *Rehabilitation Psychology*, 51, 3-12.
- Sterba, K.R., DeVellis, R.F., Lewis, M.A., DeVellis, B.M., Jordan, J.M., & Baucom, D.H. (2008). Effect of couple illness perception congruence on psychological adjustment in women with rheumatoid arthritis. *Health Psychology*, 27, 221-229.
- Stucki, G., Liang, M.H., Stucki, S., Bruhlmann, P., & Michel, B.A. (1995). A self-administered rheumatoid-arthritis disease-activity index (RADAI) for epidemiological research – psychometric properties and correlation with parameters of disease-activity. *Arthritis & Rheumatism*, 38, 795-798.
- Sullivan, M.J.L., Thorn, B., Haythornthwaite, J.A., Keefe, F., Martin, M., Bradley, L.A., et al. Theoretical perspectives on the relation between catastrophizing and pain. *Clinical Journal of Pain*, 17, 52-64.
- Turk, D.C. & Melzack, R. (Eds.). (1992). *Handbook of pain assessment*. New York: Guilford Press.
- Tzelgov, J. & Henik, A. (1991). Suppression situations in psychological research: Definitions, implications, and applications. *Psychological Bulletin*, 109, 524-536.
- Vitaliano, P.P., Zhang, J., & Scanlan, J.M. (2003). Is caregiving hazardous to one's physical health? A meta-analysis. *Psychological Bulletin*, 129, 946-972.
- Zautra, A.J., Parrish, B.P., Van Puymbroeck, C.M., Tennen, H., Davis, M.C., Reich, J.W., et al. (2007). Depression history, stress, and pain in rheumatoid arthritis patients. *Journal of Behavioral Medicine*, 30, 187-197.
- Zwicker, A. & DeLongis, A. (In press). Men and women, husbands and wives: Gender differences in stress and coping. In J. Chrisler & D. McCreary (Eds.), *Handbook of gender research in psychology*. New York: Springer Publishing Company.

APPENDICES

Appendix 1. UBC Behavioural Research Ethics Board Certificate of Approval



The University of British Columbia
Office of Research Services and Administration
Behavioural Research Ethics Board

Certificate of Approval

PRINCIPAL INVESTIGATOR Esdaile, J.		DEPARTMENT Medicine	NUMBER B05-0556
INSTITUTION(S) WHERE RESEARCH WILL BE CARRIED OUT Arthritis Research Centre of Canada ,			
CO-INVESTIGATORS: Lehman, Allen, Medicine			
SPONSORING AGENCIES			
TITLE: Rheumatoid Arthritis and the Family: An Investigation of Disease Perception			
APPROVAL DATE 11/10 - 6/2/05	TERM (YEARS) 1	DOCUMENTS INCLUDED IN THIS APPROVAL: June 2, 2005, Advertisement / Contact letter / Questionnaires / Cover letter	
CERTIFICATION: The protocol describing the above-named project has been reviewed by the Committee and the experimental procedures were found to be acceptable on ethical grounds for research involving human subjects.  <i>Approval of the Behavioural Research Ethics Board by one of the following:</i> Dr. James Frankish, Chair, Dr. Cay Holbrook, Associate Chair, Dr. Susan Rowley, Associate Chair This Certificate of Approval is valid for the above term provided there is no change in the experimental procedures			

Appendix 2. Participant recruitment posting: Arthritis Consumer Experts

Rheumatoid Arthritis and the Family: An Investigation of Disease Perceptions

Are you able to be in the study?

- Ø Yes, if you have rheumatoid arthritis (RA) and
- Ø You have a spouse or partner and
- Ø You have lived with your spouse or partner for the last year or longer

Why we contacted you?

You previously consented to getting information about research opportunities as a member of the Arthritis Consumer Experts (ACE). ACE forwarded you this letter.

Who are we?

We are researchers at the Arthritis Research Centre and the University of British Columbia.

Why be in the study?

We want to better understand how RA affects your life and your family. If you agree to participate, you and your spouse/partner will each be mailed a questionnaire about your arthritis, health, and quality of life. The results will be used to improve education programs and arthritis care. The results will be shared with arthritis researchers, health professionals, and other people with arthritis. We will also send you a copy of the results, if you so wish.

What compensation will the study provide?

Couples that return the questionnaires within 10 days will be entered into a **DRAW FOR ONE OF FIVE CASH PRIZES (1 draw of \$500, 1 draw of \$100, 3 draws of \$50).**

How long will the study take?

You will need about 30-45 minutes to finish the questionnaire. Your spouse or partner will need about 30 minutes. Both questionnaires will need to be completed separately. Your answers will not be shared with your spouse or partner.

How we maintain complete confidentiality?

Your name is not required on the questionnaire and will never appear in our data files, publications, or presentations.

Who to contact if you would like to be in the study or learn more about the study?

If you want to be in the study, please contact Allen Lehman, Research Associate at the Arthritis Research Centre, to receive the study questionnaire:

- Ø **Phone toll free (1-877-300-4555) or Vancouver local phone (604-871-4555) or**
- Ø **Email (RAresearch@arthritisresearch.ca)**

Your experiences with rheumatoid arthritis are very important to us. Your help in this study will be most appreciated.

Yours very truly,

John M. Esdaile, MD, MPH, FRCPC
Professor and Head, Division of Rheumatology,
Department of Medicine, University of British Columbia
Scientific Director, Arthritis Research Centre of Canada

Daniel Pratt, PhD
Professor, Educational Studies
University of British Columbia

Appendix 3. Participant recruitment posting: Canadian Arthritis Patient Alliance

Rheumatoid Arthritis and the Family: An Investigation of Disease Perceptions

Are you able to be in the study?

- Yes, if you have rheumatoid arthritis (RA) and
- You have a spouse or partner and
- You have lived with your spouse or partner for the last year or longer

Why we contacted you?

As a member of the Canadian Arthritis Patient Alliance (CAPA), you previously expressed an interest in receiving email bulletins about arthritis information. CAPA forwarded you this letter.

Who are we?

We are researchers at the Arthritis Research Centre and the University of British Columbia.

Why be in the study?

We want to better understand how RA affects your life and your family. If you agree to participate, you and your spouse/partner will each be mailed a questionnaire about your arthritis, health, and quality of life. The results will be used to improve education programs and arthritis care. The results will be shared with arthritis researchers, health professionals, and other people with arthritis. We will also send you a copy of the results, if you so wish.

What compensation will the study provide?

Couples that return the questionnaires within 10 days will be entered into a **DRAW FOR ONE OF FIVE CASH PRIZES (1 draw of \$500, 1 draw of \$100, 3 draws of \$50).**

How long will the study take?

You will need about 30-45 minutes to finish the questionnaire. Your spouse or partner will need about 30 minutes. Both questionnaires will need to be completed separately. Your answers will not be shared with your spouse or partner.

How we maintain complete confidentiality?

Your name is not required on the questionnaire and will never appear in our data files, publications, or presentations.

Who to contact if you would like to be in the study or learn more about the study?

If you want to be in the study, please contact Allen Lehman, Research Associate at the Arthritis Research Centre of Canada, to receive the study questionnaire:

- Phone toll free (1-877-300-4555) or Vancouver local phone (604-871-4555) or**
- Email (RAresearch@arthritisresearch.ca)**

Your experiences with rheumatoid arthritis are very important to us. Your help in this study will be most appreciated.

Yours very truly,

John M. Esdaile, MD, MPH, FRCPC
Professor and Head, Division of Rheumatology,
Department of Medicine, University of British Columbia
Scientific Director, Arthritis Research Centre of Canada

Daniel Pratt, PhD
Professor, Educational Studies
University of British Columbia

Appendix 4. Contact letter: Persons living with rheumatoid arthritis

Rheumatoid Arthritis and the Family: An Investigation of Disease Perception

Date:

Dear Sir or Madam:

We (researchers at the Arthritis Research Centre of Canada and the University of British Columbia in Vancouver) want to better understand how rheumatoid arthritis (RA) affects your life and your family. You can be in the study if you have had a doctor diagnosis of RA and if you have lived with your spouse/partner for one year or longer. We would like you to complete the attached questionnaire. This will take about 30-45 minutes. The questions are about arthritis, health, and quality of life. Please return your questionnaire in the enclosed prepaid envelope – no stamp is necessary. This will indicate that you have agreed to participate in the study.

Please give the envelope labeled spouse/partner to your spouse or partner so that they can complete their questionnaire. Your spouse or partner will be asked to return their questionnaire in a different prepaid envelope. It is very important that you and your spouse or partner complete the questionnaires separately. Please do not discuss the questions until after you have both mailed your questionnaires back to us. Couples that return the questionnaires within 10 days will be entered into a DRAW FOR FIVE CASH PRIZES (1 draw of \$500, 1 draw of \$100, 3 draws of \$50).

The benefits of the study are that the results will be used to improve education programs and arthritis care. The experiences of people with RA and their families will be shared with arthritis researchers, health professionals, and other people with arthritis. We will also send you a copy of the results, if you so wish. The results will be based on the average responses of all people who are in the study, and not the specific answers of one person.

There are no risks if you choose to participate in the study. If you choose not to return the questionnaire, or decide not to finish it once you have begun, your decision will be respected and in no way affect your health care. Your name is not required on the questionnaires and will never appear in our data files, publications, or presentations. Your answers will be identified by a number code. Your answers to questions will not be shared with your spouse or partner. All data will be stored in a locked cabinet and computer files will be password protected. You will not be committing to any further questionnaires or studies by participating.

If you have any concerns about your rights as a research participant, you may contact the Research Subject Information Line in the University of British Columbia (UBC) Office of Research Services at (604) 822-8598. If you have any questions about the study, please contact Allen Lehman, Research Associate at the Arthritis Research Centre

(604) 871-4555). If you do not want to be contacted again about this study, please phone Mr. Lehman. Mr. Lehman is working on this study as part of his doctoral studies at UBC. The principal investigators for the study are Dr. John Esdaile (Professor and Head, Division of Rheumatology, Department of Medicine, UBC and Scientific Director of the Arthritis Research Centre of Canada), Dr. Dan Pratt (Professor of Educational Studies at UBC) and other co-investigators include Dr. Anita DeLongis (Associate Professor, Psychology, UBC) and Dr. John Collins (Adjunct Professor, Educational Studies, UBC).

Your experiences with rheumatoid arthritis are very important to us. Your help in this study will be most appreciated.

Yours very truly,

John M. Esdaile, MD, MPH, FRCPC
Professor and Head, Division of Rheumatology,
Department of Medicine, University of British
Columbia
Scientific Director, Arthritis Research Centre of Canada
Tel: 604-871-4563

Daniel Pratt, PhD
Professor, Educational Studies
University of British
Columbia
Tel: 604-822-4552

Appendix 5. Contact letter: Spouses of persons living with rheumatoid arthritis

Rheumatoid Arthritis and the Family: An Investigation of Disease Perception

Date:

Dear Sir or Madam:

We (researchers at the Arthritis Research Centre of Canada and the University of British Columbia in Vancouver) want to better understand how your spouse or partner's rheumatoid arthritis (RA) affects them and you. Your spouse or partner with RA already received a separate questionnaire to complete. We would like you to complete the attached questionnaire (this will take about 30 minutes). The questions are about arthritis, health, and quality of life. Please return your questionnaire in the enclosed prepaid envelope – no stamp is necessary. This will indicate that you have agreed to participate in the study.

Your spouse/partner will be asked to return their questionnaire in a different prepaid envelope. It is very important that you and your spouse/partner complete the questionnaires separately. Please do not discuss the questions until after you both have mailed your questionnaires back to us. Couples that return the questionnaires within 10 days will be entered into a DRAW FOR FIVE CASH PRIZES (1 draw of \$500, 1 draw of \$100, 3 draws of \$50).

The benefits of the study are that the results will be used to improve education programs and arthritis care. The experiences of people with RA and their families will be shared with arthritis researchers, health professionals, and other people with arthritis. We will also send you a copy of the results, if you wish. The results will be based on the average responses of all people who are in the study, and not the specific answers of one person.

There are no risks if you choose to participate in the study. If you choose not to return the questionnaire, or decide not finish it once you have begun, your decision will be respected and in no way affect your or your spouse/partner's health care. Your name is not required on the questionnaire and will never appear in our data files, publications, or presentations. Your answer will be identified by a number code. Your answers to questions will not be shared with your spouse/partner. All data will be stored in a locked cabinet and computer files will be password protected. You will not be committing to any further questionnaires or studies by participating.

If you have any concerns about your rights as a research participant, you may contact the Research Subject Information Line in the University of British Columbia (UBC) Office of Research Services at (604) 822-8598. If you have any questions about the study, please contact Allen Lehman, Research Associate at the Arthritis Research Centre (604) 871-4555). If you do not want to be contacted again about this study, please phone

Mr. Lehman. Mr. Lehman is working on this study as part of his doctoral studies at UBC. The principal investigators for the study are Dr. John Esdaile (Professor and Head, Division of Rheumatology, Department of Medicine, UBC and Scientific Director of the Arthritis Research Centre of Canada), Dr. Dan Pratt (Professor of Educational Studies at UBC) and other co-investigators include Dr. Anita DeLongis (Associate Professor, Psychology, UBC) and Dr. John Collins (Adjunct Professor, Educational Studies, UBC).

Your experiences living with a person who has rheumatoid arthritis are very important to us. Very few studies have ever asked to hear the perspectives of people who live with somebody that has arthritis. Your help in this study will be most appreciated.

Yours very truly,

John M. Esdaile, MD, MPH, FRCPC
Professor and Head, Division of Rheumatology,
Department of Medicine, University of British
Columbia
Scientific Director, Arthritis Research Centre of Canada
Tel: 604-871-4563

Daniel Pratt, PhD
Professor, Educational Studies
University of British
Columbia
Tel: 604-822-4552