Parenting disability, parenting stress and child behaviour in early inflammatory arthritis

P. Zelkowitz, EdD (1); K. J. Looper, MD (1); S. S. Mustafa, PhD (1); M. Purden, PhD (2); M. Baron, MD (3); McGill Early Arthritis Research Group***

This article has been peer reviewed.

Abstract

Introduction: Our study examines the association between the disease characteristics of inflammatory arthritis and patients' self-perception of mental health, parenting disability, parenting stress and child behaviour in early inflammatory arthritis (EIA).

Methods: Patients in the early phase (more than 6 weeks, less than 18 months) of inflammatory arthritis were recruited from a larger EIA registry that recorded sociodemographic data and measures of pain, physical functioning and disease activity. Patient-perceived parenting disability, parenting stress, depression and children's behaviour problems were assessed using the Parenting Disability Index, Parenting Stress Index, Center for Epidemiologic Studies - Depression Mood Scale and Child Behavior Checklist, respectively.

Results: Pain, physical dysfunction, number of tender joints and physician global assessment of disease activity were associated with parenting disability. Self-report measures of parenting disability were associated with those of depression and parenting stress. Parenting stress was associated with children internalizing and externalizing behaviour problems while parenting disability was associated with children externalizing behaviour problems.

Conclusion: This study suggests a possible reciprocal relationship among physical aspects of disease activity, parenting disability and parent and child distress in EIA.

***Keywords:** parenting disability, parenting stress, child behaviour, arthritis, physical functioning, pain*

Introduction

Arthritis comprises more than a hundred rheumatic conditions involving joints and their surrounding tissues. Inflammatory arthritis occurs when joints get inflamed because of immune system disruptions. It is a painful disabling condition associated with impairment in psychological and social functioning.[1,2] Rheumatoid arthritis (RA) is the most common form of inflammatory arthritis and is characterized by chronic destructive synovitis. Undifferentiated arthritis is one that does not fulfill disease classification criteria and can ultimately either resolve or else evolve to full-blown rheumatoid arthritis.

Physical illness in a parent can affect children in many ways. The parent may be unable to perform usual childcare tasks and may, in fact, expect children to take on additional household responsibilities.[3] Moreover, the parent may be emotionally unavailable due to pain, fatigue and preoccupation with the disease.[4,5] Family stress related to possible loss of income or marital conflict around changing roles and division of labour may also take its toll on the parent-child relationship.[6] Children's adjustment is most likely to be affected if the ill parent exhibits psychological distress[4] and if parenting behaviour is affected.[5]

Research in families with a parent suffering from arthritis has been limited, but what is available indicates significant negative effects. For example, an exploratory study by Grant et al.[7] showed that parents and grandparents with RA experience difficulties with instrumental childcare tasks such as lifting a child. Katz et al.[8] found that women with RA experience disability in parenting activities and hence perform fewer parenting functions. Backman et al[9] qualitatively examined the experiences of mothers living with arthritis and described the impact of inflammatory arthritis on motherhood as dramatic, with both positive and negative influences. They described participation in the mothering role as fluctuating and influenced by the support available and the unpredictable balance of fatigue and energy.[9] This resulted in the family being more cohesive at certain times and feeling regret about lost family activities at other times.[9]

---

* M. Starr, MD; M. Gagné, MD; M. Stein, MD; H. Kang, MD; M. Kapusta, MD; F. Couture, MD; M. A. Fitzcharles, MD; B. Garfield, MD; H. A. Ménard, MD; L. Berkson, MD; C. Pineau, MD; A. Gutkowski, MD; M. Zummer, MD; J. P. Mathieu, MD; S. Mercille, MD; S. Ligier, MD; J. Krasny, MD; C. Bertrand, MD; S. Y. Yuen, MD; J. Schulz, MD.

Author references:

1. Department of Psychiatry, McGill University, Montréal, Quebec, Canada
2. Department of Nursing, McGill University, Montréal, Quebec, Canada
3. Department of Rheumatology, McGill University, Montréal, Quebec, Canada

Correspondence: Karl Looper, Department of Psychiatry, McGill University, Jewish General Hospital, 3755 Chemin de la Côte-Ste-Catherine, Montréal, QC H3T 1E2; Tel.: 514-340-8222; Fax: 514-230-8126; Email: karl.looper@mcgill.ca

Arthritis patients often perceive themselves as functioning inadequately with regard to their children and grandchildren.[10] One study reported that children of RA patients had more daily hassles, smaller social support networks and poorer social adjustment than did the controls.[11] Adolescent children of a parent with RA reported lower self-esteem than those of well parents.[12]

Much of the research in this area has consisted of small, qualitative studies. Moreover, it usually involved patients who have been ill for many years. However, parenting issues may be different in early versus longstanding inflammatory arthritis. Clearly needed is research examining the relationship between parenting and children, mental health, and illness outcomes early in the disease trajectory, with the aim of developing treatment interventions directed at specific factors in the early stage of illness to improve subsequent health and parenting outcomes.

To that end, we undertook this study to explore the associations between disease variables such as pain, physical dysfunction and disease activity, mental distress, parenting factors such as parenting ability and parenting stress, and child behavioural measures during the first 18 months of the parents' inflammatory arthritis.

Methods

Participants

Two hundred and fifty-seven patients were enrolled in the McGill Early Arthritis Registry (McEAR) between March 2006 and May 2009. Referrals to the McEAR come from 21 rheumatologists working in Montréal, Quebec. The participating rheumatologists, each of whom works in a private office or outpatient hospital clinic, were asked to recruit all new patients with early inflammatory arthritis (EIA) who fit the inclusion criteria, that is, they had newly diagnosed inflammatory arthritis, defined as one or more joints with inflammation that lasted a minimum of 6 weeks to a maximum of 18 months. (Disease duration was assessed by asking the patient ''When did you first start to have this episode of joint pain?'' and ''Have you ever had episodes of similar pain and swelling in your joints before this episode?'') Patients were 18 years or older, spoke English or French, and agreed to periodic physical and laboratory examinations as well as to completing questionnaires assessing demographics, disability, pain and psychosocial factors related to their illness. Exclusion criteria included clinical evidence of remote joint damage suggestive of a previous episode of RA, any rheumatic diagnosis other than RA or undifferentiated inflammatory arthritis, severe functional limitation from a disease other than arthritis, and any disorder that compromised the ability to give informed consent.

Of the 257 patients enrolled in the McEAR, 80 had children younger than 18 years of age living with them. All the 257 patients enrolled in the McEAR were invited to participate in psychosocial studies, which involved a home visit by interviewers, and 104 (40.5%) agreed to do so. Of the 104 participants, 29 had children aged less than 18 years living with them. All of those 29 parent participants agreed to participate and constituted the sample for this study, a response rate of 36% (29/80 of the McEAR participants who had children under 18 years) when considering the McEAR as a whole and 100% of those who agreed to the psychosocial study.

All patients in the registry were seen by one of the two study nurses who met them at the office of the referring rheumatologist with whom the clinical care remained. (This made it easier for those patients who lived on or near the island of Montreal.) Each nurse was trained to perform a complete tender and swollen joint count. Nurses, physicians and patients were not blind to one another's evaluations.

A trained interviewer, blind to patients' information recorded in the main registry database, arranged to see the patient at home within 10 days of the registry visit for this study. The trained interviewer obtained consent to proceed with the interview and assisted the patients in filling out the study-specific questionnaires. Patients received $25 for each meeting with the study interviewer. All patients in the McEAR signed an informed consent and the study was approved by the Institutional Review Boards of McGill University and the Jewish General Hospital.

Illness outcome measures

Physical functioning

We measured physical functioning using the Medical Outcomes Study Short-Form 36 (SF-36)[13] which, with its good psychometric properties, has been frequently used to measure health-related quality of life. It consists of eight domains: physical functioning, social functioning, role limitations (physical problems), role limitations (emotional problems), mental health, vitality, bodily pain and general health perceptions. Scores range from 0 (worst) to 100 (best). Although the 8 scales are combined into 2 summary measures, one of which, the Physical Component Score (SF36-PCS), provides an overall estimate of physical health, we chose to measure physical function using the physical functioning domain score. We measured pain more specifically using the McGill Pain Questionnaire (MPQ). [14]

Pain

Pain was assessed using the Short-Form MPQ,[15] which contains 11 items related to the sensory dimension of pain and 4 related to the affective dimension. Each descriptor is ranked on a four-point intensity scale (0–3; none to severe), and total scores range from 0 (no pain) to 45 (severe pain). The MPQ has been extensively used and has sound psychometric properties. The total pain score was used in this study.

Disease activity

We assessed disease activity using joint counts, with the number of swollen and tender joints determined according to the American College of Rheumatology joint count.[16] We also measured blood level of the acute-phase reactant, C-reactive protein (CRP). Number of swollen joints, number of tender joints, patient global assessment of disease activity and blood CRP level together make up the Disease Activity Score in 28 joints (DAS28).[17–20]

DAS28, based on 28 specific joints that are a subset of the American College of Rheumatology criteria, was developed[17] and validated[18] for patients with RA and is considered to be a valid measure of disease activity.[18] The validation criteria included correlations with a selected group of other disease variables (correlational validity), with physical disability and judgment of a group of rheumatologists in clinical practice (criterion validity I and II, respectively) and with the radiographically determined damage of hands and feet (construct validity).[18] DAS28, however, excludes joints of the ankles and feet.[21]

In our study, we completed the patient global assessment of disease activity using an 11-point visual analogue scale that ranged from 0 (best) to 10 (worst) with reference to the past week. The rheumatologist rated the physician global assessment of disease activity using a single 11-point numerical rating scale where 0 meant ''no arthritis activity'' and 10 meant ''worst arthritis.''

Psychosocial measures and parenting and child functioning measures

Center for Epidemiologic Studies - Depression Mood Scale

The Center for Epidemiologic Studies – Depression Mood Scale (CES-D) is a 20-item self-report scale designed to measure depression in the general population.[22] Answers are based on how frequently in the previous week each item was experienced. Scores range from 0 to 60, with higher scores indicating greater depression. A cut-off score of 16 is the requirement for identifying depression, but in chronic disease such as RA, cut-offs of 19 have been recommended.[23,24] In our study, we used the total score (continuous variable) to measure symptom severity.

Parenting Stress Index

The Parenting Stress Index (PSI) (Short Form)[25] is a 36-item self-report measure assessing parental distress. It has 3 subscales, Parental Distress, Parent-Child Dysfunctional Interaction and Difficult Child. Each item is rated from 1 (''strongly disagree'') to 5 (''strongly agree''). Higher scores indicate greater stress. Cronbach's α ranges from .88 to .95, and the scale has construct validity compared to measures of children's behaviour problems.[25] We used the total score in this study.

Parenting Disability Index

The Parenting Disability Index (PDI) was developed as a measure of parenting function and disability and validated in women with RA.[8] The 27 items on the scale are scored from 0 to 3, with 0 meaning no disability and 3 meaning inability to perform parenting tasks. The PDI is the mean difficulty level across the domains within the parent cohort/child age group. Two summary scores were developed; the summary score used in this study is the modified PDI (MPDI).[8] This scale was validated in an RA population.

Child Behavior Checklist

The Child Behavior Checklist (CBCL)[26,27] was used to assess children's behaviour problems, using the relevant versions for children aged 1.5 to 5 years and 6 to 18 years. Parents rate their children's behaviour over the previous 2 months. Items are scored 0 for ''not true'' to 2 for ''very or often true.'' Both versions have 3 broadband (summary) scores representing internalizing problems, externalizing problems and total problems. Internalizing problems include anxiety, depression and somatic symptoms, while externalizing problems include conduct problems, hyperactivity and aggression. Test-retest reliabilities range from .88 to .91 for the broadband scales, and the interrater reliability for the CBCL is .72 for internalizing problems and .85 for externalizing problems.[26] We used internalizing and externalizing scores for both age groups. To obtain comparable data, if there were 2 or more children residing at home, parents were asked to rate the behaviour of the child closest in age to 10 years.

Statistical analysis

Because of the small sample size ($n = 29$), data analyses in this study must be considered exploratory. Data were analyzed using SPSS version 17 for Windows (IBM, Chicago, IL, US). Descriptive statistics were used to summarize baseline characteristics of the EIA patients. Pearson correlations were used to calculate the associations between the continuous study variables. Missing data was not imputed, and we did not include cases for which data were missing in our calculations.

Results

The mean age of our study participants was almost 42 years; 20 (69%) were female and 23 (79%) were married/cohabiting. A total of 21 (72%) participants were employed; 14 were working full time, 3 were on sick leave, 2 were working part time and 2 were self-employed. The total yearly household income of more than half of the participants was over $60,000. The sample was highly educated with 20 (69%) college, university or postgraduate educated. Out of our 29 participants, 15 (52%) had 1 child, 10 (35%) had 2 children and 4 (14%) had 3 children aged under 18 years living at home. Our participants had an average disease duration (standard deviation) of 8.24 (3.65) months. Four participants (14%) had a CES-D score above the cut-off of 19. (See Table 1.)

The average age of the target child was 10.6 years. The proportion of boys and girls was almost equally distributed along the sample, and 48% of the target children (those closest in age to 10 years) were girls. Three children scored above the clinical cut-off of 60 on CBCL internalizing and externalizing problems.

Parenting stress (PSI) was significantly correlated only to CES-D total depressive mood score. On the other hand, patient-perceived parenting disability (MPDI) was correlated to all the disease measures: physician global assessment of disease activity, number of tender joints, physical dysfunction (SF-36) and pain (MPQ) in addition to depressive mood (CES-D). Patient-perceived children's externalizing and internalizing behaviour problems (CBCL, all ages) showed significant correlation to physician global assessment of disease activity. Parental depressive symptoms were not associated with children's behaviour problems. Table 2 shows the

TABLE 1
Characteristics of study participants (N = 29)

Study variable	Frequency, n (%)	Mean (SD)	95% Confidence interval
Demographics			
Age, years		41.97 (7.95)	26–57
Female	20 (69)		
Married/co-habiting	23 (79)		
Employed	21 (72)		
Yearly household income			
< $60,000	11 (38)		
≥ $60,000	17 (59)		
Education level			
High school or less	9 (31)		
College or more	20 (69)		
Number of children			
1	15 (52)		
2	10 (35)		
3	4 (14)		
Age of target child[a]		10.60 (5.10)	1.00–18.00
Gender of target child[a]: girl	13 (48)		
Disease characteristics			
Duration, months		8.24 (3.65)	4.00–18.00
SF-36 physical functioning		60.04 (28.90)	5.00–100.00
MPQ total pain		8.60 (11.17)	0.00–45.00
Number of swollen joints		9.19 (9.56)	0.00–39.00
Number of tender joints		16.00 (12.76)	0.00–43.00
CRP, mg/L		22.87 (22.49)	0.30–69.00
DAS28		5.30 (1.80)	2.61–8.08
Physician global assessment of disease activity		3.96 (2.71)	0.00–10.00
Psychosocial variables			
CES-D total depressive mood		10.03 (10.58)	0.00–41.00
PSI		63.89 (19.43)	36.00–100.00
MPDI for all ages		0.65 (0.61)	0.00–1.95
CBCL, externalizing problems, all ages		47.96 (8.18)	34.00–65.00
CBCL, internalizing problems, all ages		50.55 (11.39)	33.00–78.00

Abbreviations: CBCL, Child Behavior Checklist; CES-D, Center for Epidemiologic Studies - Depression Mood Scale; CRP, C-reactive protein; DAS28, Disease Activity Score in 28 joints; MPDI, Modified Parenting Disability Index; MPQ, McGill Pain Questionnaire; PSI, Parenting Stress Index; SF-36, Medical Outcomes Study Short Form 36; SD, standard deviation.

[a] To obtain comparable data, if there were 2 or more children residing at home, parents were asked to rate the behaviour of the child closest in age to 10 years.

relationships between parents' physical and mental health and parenting and child behaviour problems.

Parenting stress (PSI) was significantly correlated to parenting disability (MPDI) and children's internalizing and externalizing (CBCL) problems. Patient-perceived parenting disability (MPDI) showed significant correlation to children's externalizing (CBCL) problems in addition to parenting stress. Table 3 shows the interrelationships between parenting and child behaviour variables.

Other disease-related variables including the number of swollen joints, CRP and the DAS28 did not show significant correlations with any of the parenting or child behaviour measures.

Discussion

Parenting is both physically and emotionally extremely demanding.[28] Given the scarcity of literature on how chronically ill arthritis patients who have young children manage both their illness and parenting, we sought to examine the relationship between arthritis in its early stages (between 6 weeks and 18 months) and patients' self-rated distress, ability to perform parenting tasks and perception of their child's behaviour.

The main findings of this study indicate that arthritis, even in its early stages, does interfere with parenting. Our patients suffered increased parenting disability with the increase in multiple measures of disease activity including pain, physical dysfunction, number of tender joints and physicians' assessment of disease activity. Patients reported having difficulties with, among others, bending, outdoor activities or having other children in their home. This perceived inability to parent adequately may have resulted in feelings of distress. This is suggested by the fact that parenting disability was highly correlated with parenting stress and both of these factors were related to CES-D depressive mood score.

These findings are consistent with previous research in more advanced RA patients.[7,8] These studies found that many patients had problems with parenting, particularly with tasks related to physical care activities such as lifting a child from the floor and keeping up with children. These problems are often attributed to physical as well as psychological issues such as anxiety, depression and guilt. White et al.[29] also found that for mothers with RA, more fatigue was a significant predictor of greater frequency and intensity of daily parenting problems and greater difficulty monitoring their children's whereabouts.[29] Mothers with RA had more problems monitoring their child if they were more depressed and experiencing an exacerbation.[29] Our results also agree with those of a very recent study[30] that investigated the impact of systemic lupus erythematosus on mothering abilities. The authors reported that greater fatigue and func-

TABLE 2
Pearson product moment correlations (*r*) among study variables[a]

Statistics		Parental health disease measure				
		CES-D total depressive mood	Physician global assessment of disease activity	Number of tender joints	SF-36 physical functioning	MPQ total pain
Parenting variables						
Parenting Stress Index (PSI)	*r*	.565**	.360	.039	−.149	.045
	p	.002	.077	.874	.488	.834
	n	27	25	19	24	24
Parenting Disability Index (MPDI)	*r*	.716**	.648**	.541*	−.608**	.455*
	p	<.001	.001	.025	.003	.038
	n	24	22	17	21	21
Child behaviour problems (CBCL)						
Internalizing	*r*	.348	.503*	.017	−.148	−.020
	p	.113	.020	.951	.546	.934
	n	22	21	15	19	19
Externalizing	*r*	.363	.441*	.016	−.274	−.092
	p	.074	.035	.950	.218	.684
	n	25	23	18	22	22

Abbreviations: CBCL, Child Behavior Checklist; CES-D, Center for Epidemiologic Studies - Depression Mood Scale; MPDI, Modified Parenting Disability Index; MPQ, McGill Pain Questionnaire; PSI, Parenting Stress Index; SF-36, Medical Outcomes Study Short Form 36.

[a] Data on depression, pain, physical functioning, parenting stress, parenting disability, and children's behaviour problems based on patients' perceptions.

* Correlation is significant at the 0.05 level (2-tailed).

** Correlation is significant at the 0.01 level (2-tailed).

tional disability resulted in higher PDI scores in mothers with children aged less than 18 years living with them. The mean disease duration of those mothers was 7 years. In our study we were able to detect the association between patient-perceived parenting disability and disease variables within 8 months, on average, from the onset of illness.

The patients' reduced parenting efficacy and concomitant psychological distress also affected their children. Children whose parents had more physician-rated disease activity were rated by those parents as exhibiting more externalizing and internalizing behavioural problems. Parenting stress was associated with both internalizing and externalizing problems while parenting disability was correlated only with externalizing problems. It is possible that children whose parents are less well able to supervise and care for them will be prone to more non-compliant, aggressive behaviour. In a study by Welch et al.[31] parents recently diagnosed with cancer did not detect emotional or behavioural problems on the CBCL scale in their children; however, their children, especially adolescent girls, reported symptoms of anxiety/depression and aggressive behaviour.[31] These findings indicate that future studies should include children's self-reports along with their parents' in order to achieve a more complete picture of child distress in response to parental chronic illness.

TABLE 3
Pearson product moment correlations (*r*) between parenting and child behaviour variables

Statistics		Parenting variables		Child behaviour variables	
		PSI	MPDI	CBCL – internalizing	CBCL – externalizing
Parenting Stress Index (PSI)	*r*	—	.441*	.537**	.572**
	p	—	.031	.010	.003
	n	—	24	22	25
Parenting Disability Index (MPDI)	*r*	—	—	.232	.486*
	p	—	—	.325	.022
	n	—	—	20	22
Child behaviour problems (CBCL) Internalizing	*r*	—	—	—	.759**
	p	—	—	—	.000
	n	—	—	—	22

Abbreviations: CBCL, Child Behavior Checklist; MPDI, Modified Parenting Disability Index; PSI, Parenting Stress Index.

* Correlation is significant at the 0.05 level (2-tailed).

** Correlation is significant at the 0.01 level (2-tailed).

That physician global assessment of disease activity—and not measures of function, pain or joint counts—relates to the patients' perceptions of their children's externalizing and internalizing behaviour could indicate that patients' reports of distress about parenting have some influence on physicians' global assessment. Rheumatologists could be invited to refer patients to allied health care professionals for further assessment on an individualized basis.

Limitations

Our study was limited by a small sample size (n = 29). Only 30% of the participants in the McEAR registry had children under 18 living at home. Since our study was concerned with parenting, we were unavoidably limited to those patients with children living at home with them. We thus lacked power to detect significant associations among the study variables. For example, it was not possible to explore differences in employment status as well as other non-work responsibilities that may have affected parenting stress and mood. Nevertheless, we were able to demonstrate significant relationships between parental mood and parenting, as well as between disease activity and parenting behaviour.

This study was cross-sectional and therefore did not allow for estimation of the causal direction of the observed associations. Longitudinal studies are required to assess how disease progression may affect the parent-child relationship as well as child outcomes. However, based on previous research reporting that disability in valued life activities is a strong predictor of the subsequent development of depressive symptoms and that depressive symptoms lead to lower parental functioning,[32] we speculate that disability in parenting activities would be associated with psychological distress with consequent negative effects on the children.

A third limitation of our study is the use of parental reporting of their own psychological and physical symptoms as well as child outcomes, which may result in shared method variance. Future research should follow the families longitudinally to see how disease progression or improvement following a course of treatment affects the parent-child relationship and child outcomes. Moreover, it would be useful to obtain information from the children themselves and also to have independent ratings by teachers or other knowledgeable informants.

Finally, recent research suggested that the DAS28 may underestimate disease activity in some RA patients with disease onset mainly in the feet and particularly during the first 2 years of the disease.[21]

Conclusion

Our study pointed towards the potential inability of parents to provide their children with quality care due to their arthritis-induced pain, physical dysfunction and disease activity. This patient-perceived physical impairment was associated with psychological distress in the parents and patient-perceived behaviour problems in the children, which highlights the interrelatedness and complexity of the relationships between parents' physical health, psychological health and parent-child interactions. A multifaceted approach to the care for parents with arthritis is called for. It is important to manage not only the physical symptoms of arthritis, but also the emotional distress attendant upon the pain and functional impairment associated with the disease. Backman et al. [9] suggested some strategies that might help parents with arthritis fulfill their parenting role. These include adjusting expectations, adaptive or alternative approaches to performing parenting tasks, public health interventions and credible advice grounded in the experiences of parents living with arthritis.[9] Reframing and explaining illness behaviour to children[33] and encouraging mature child behaviour[34] could also be beneficial.

Acknowledgements

This study was supported by grant 8455 from the Fonds de la recherché en santé du Québec.

References

1. Anderson KO, Bradley LA, Young LD, McDaniel LK, Wise CM. Rheumatoid arthritis: review of psychological factors related to etiology, effects, and treatment. Psychol Bull. 1985;98(2):358–87.

2. Fex E, Larsson BM, Nived K, Eberhardt K. Effect of rheumatoid arthritis on work status and social and leisure time activities in patients followed 8 years from onset. J Rheumatol. 1998;25(1):44–50.

3. Lundwall RA. Parents' perceptions of the impact of their chronic illness or disability on their functioning as parents and on their relationships with their children. Fam J. 2002;10(3):300–7.

4. Korneluk YG, Lee CM. Children's adjustment to parental physical illness. Clin Child Fam Psychol Rev. 1998;1(3):179–93.

5. Sigal JJ, Perry JC, Robbins JM, Gagne MA, Nassif E. Maternal preoccupation and parenting as predictors of emotional and behavioral problems in children of women with breast cancer. J Clin Oncol. 2003;21(6):1155–60.

6. Rolland JS. Parental illness and disability: a family systems framework. J Fam Ther. 1999;21(3):242–66.

7. Grant MI, Foster NE, Wright CC, Barlow JH, Cullen LA. Being a parent or grandparent with back pain, ankylosing spondylitis or rheumatoid arthritis: a descriptive postal survey. Musculoskeletal Care. 2004;2(1):17–28.

8. Katz PP, Pasch LA, Wong B. Development of an instrument to measure disability in parenting activity among women with rheumatoid arthritis. Arthritis Rheum. 2003;48(4):935–43.

9. Backman CL, Smith L del F, Smith S, Montie PL, Suto M. Experiences of mothers living with inflammatory arthritis. Arthritis Rheum. 2007;57(3):381–8.

10. Barlow JH, Cullen LA, Foster NE, Harrison K, Wade M. Does arthritis influence perceived ability to fulfill a parenting role? Perceptions of mothers, fathers and grandparents. Patient Educ Couns. 1999;37(2):141–51.

11. Turner Cobb JM, Steptoe A, Perry L, Axford J. Adjustment in patients with rheumatoid arthritis and their children. J Rheumatol. 1998;25(3):565–71.

12. Hirsch BJ, Moos RH, Reischl TM. Psychosocial adjustment of adolescent children of a depressed, arthritic, or normal parent. J Abnorm Psychol. 1985;94(2):154–64.

13. McHorney CA, Ware JE Jr, Raczek AE. The MOS 36-Item Short-Form Health Survey (SF-36): II. Psychometric and clinical tests of validity in measuring physical and mental health constructs. Med Care. 1993;31(3):247–63.

14. Melzack R. The McGill Pain Questionnaire: major properties and scoring methods. Pain. 1975;1(3):277–99.

15. Melzack R. The short-form McGill Pain Questionnaire. Pain. 1987;30(2):191–7.

16. Felson DT, Anderson JJ, Boers M, Bombardier C, Chernoff M, Fried B, et al. The American College of Rheumatology preliminary core set of disease activity measures for rheumatoid arthritis clinical trials. The Committee on Outcome Measures in Rheumatoid Arthritis Clinical Trials. Arthritis Rheum. 1993;36(6):729–40.

17. van der Heijde DM, van't Hof MA, van Riel PL, Theunisse LA, Lubberts EW, van Leeuwen MA, et al. Judging disease activity in clinical practice in rheumatoid arthritis: first step in the development of a disease activity score. Ann Rheum Dis. 1990; 49(11):916–20.

18. van der Heijde DM, van't Hof MA, van Riel PL, van Leeuwen MA, van Rijswijk MH, van de Putte LB. Validity of single variables and composite indices for measuring disease activity in rheumatoid arthritis. Ann Rheum Dis. 1992;51(2):177–81.

19. van der Heijde DM, van Riel PL, van Leeuwen MA, van't Hof MA, van Rijswijk MH, van de Putte LB. Prognostic factors for radiographic damage and physical disability in early rheumatoid arthritis. A prospective follow-up study of 147 patients. Br J Rheumatol. 1992;31(8):519–25.

20. Wijnands MJ, van't Hof MA, van Leeuwen MA, van Rijswijk MH, van de Putte LB, van Riel PL. Long-term second-line treatment: a prospective drug survival study. Br J Rheumatol. 1992;31(4):253–8.

21. Bakker MF, Jacobs JW, Kruize AA, van der Veen MJ, van Booma-Frankfort C, Vreugdenhil SA, et al. Misclassification of disease activity when assessing individual patients with early rheumatoid arthritis using disease activity indices that do not include joints of feet. Ann Rheum Dis. 2012;71(6):830–5.

22. Radloff LS. The CES-D scale. A self-report depression scale for research in the general population. Appl Psychol Meas. 1977;1(3): 385–401.

23. Martens MP, Parker JC, Smarr KL, Hewett JE, Slaughter JR, Walker SE. Assessment of depression in rheumatoid arthritis: a modified version of the center for epidemiologic studies depression scale. Arthritis Rheum. 2003;49(4):549–55.

24. McQuillan J, Fifield J, Sheehan TJ, Reisine S, Tennen H, Hesselbrock V, et al. A comparison of self-reports of distress and affective disorder diagnoses in rheumatoid arthritis: a receiver operator characteristic analysis. Arthritis Rheum. 2003;49(3): 368–76.

25. Abidin RR. Parenting stress index short form, 3rd ed: test manual. University of Virginia (36-item version). Odessa (FL): Psychological Assessment Resources, Inc; 1995.

26. Achenbach TM. Child behavior checklist for ages 6–18. Burlington (VT): University of Vermont, Research Center for Children, Youth, & Families; 2001.

27. Achenbach TM, Ruffle TM. The Child Behavior Checklist and related forms for assessing behavioral/emotional problems and competencies. Pediatr Rev. 2000;21(8): 265–71.

28. Umberson D. Relationships with children: explaining parents' psychological well-being. J Marriage Fam. 1989;51(4):999–1012.

29. White CP, White MB, Fox MA. Maternal fatigue and its relationship to the caregiving environment. Fam Syst Health. 2009; 27(4):325–45.

30. Poole JL, Rymek-Gmytrasiewicz M, Mendelson C, Sanders M, Skipper B. Parenting: the forgotten role of women living with systemic lupus erythematosus. Clin Rheumatol. 2012;31:995–1000.

31. Welch AS, Wadsworth ME, Compas BE. Adjustment of children and adolescents to parental cancer. Parents' and children's perspectives. Cancer. 1996;77(7):1409–18.

32. Pakenham KI, Cox S. Test of a model of the effects of parental illness on youth and family functioning. Health Psychol. 2011; forthcoming.

33. Allaire S. How a chronically ill mother manages. Am J Nurs. 1988;88(1):46–9.

34. White CP, Mendoza J, White MB, Bond C. Chronically ill mothers experiencing pain: relational coping strategies used while parenting young children. Chronic Illn. 2009;5(1):33–45.