

Association of the Commitments and Responsibilities of the Caregiver Within the Family to the Disease Activity in Patients With Rheumatoid Arthritis: A Report From Turkey

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ABSTRACT

Objectives: This study aims to investigate the commitments and responsibilities of the family caregiver of rheumatoid arthritis (RA) patients and determine the association of these to the disease activity.

Patients and methods: The study included a total of 240 subjects, consisting of 60 RA patients (8 males, 52 females; mean age 50.4±11.1 years; range 25 to 76 years) with their respective 60 primary caregivers (42 males, 18 females; mean age 43.1±15.3 years; range 12 to 77 years) and 60 osteoarthritis patients (7 males, 53 females; mean age 62.8±9.0 years; range 45 to 85 years) with their respective 60 primary caregivers (38 males, 22 females; mean age 47.6±13.2 years; range 27 to 87 years). Disease severity and pain of patients were assessed through visual analog scale (VAS). Sedimentation and C-reactive protein values were recorded during routine visits. Patients were stratified by disease activity that was determined by disease activity score 28 (DAS28). Caregivers of patients evaluated disease severity and pain by VAS, and completed Caregiver Reaction Assessment (CRA) and Caregiver Strain Index (CSI) questionnaires. For a more objective assessment, tasks related to care, household, and assistance and allocated time periods for each group of tasks were queried.

Results: When CRA and CSI were compared in terms of disease activity, patients significantly differed in impact on schedule subscale of CRA ($p<0.05$). Similarly, disease activity was significantly associated with impact on finance subscale of CRA ($p<0.05$). Impact on health subscale of CRA was also correlated with disease activity; i.e., the higher the DAS28, the more negative impact on health of the caregiver.

Conclusion: Patient care is an important part of RA management. Chronic diseases form commitment on patient's caregiver. That the care of the patient may be associated with many factors related to both the patient and the caregiver should not be underestimated. We suggest that caregiver's strain may be correlated with disease activity.

Keywords: Caregiver Reaction Assessment; Caregiver Strain Index; disease activity score 28; osteoarthritis; rheumatoid arthritis.

Rheumatoid arthritis (RA) is a multi-organ disease characterized by progressive synovial tissue inflammation with bone erosions, cartilage destruction, and disrupted integrity of the joint.¹ Its prevalence ranges from 0.5 to 1.0%,² with a female predominance of 2-4:1 over male patients.³ The disease mainly affects young adults, where 80% of patients are aged between 35-50 years old. Sex difference tends to diminish by increasing age.³ Typically having an insidious onset and affecting middle-aged females, RA is

a chronic systemic disease characterized by pain, stiffness, and symmetrical swelling of small joints, especially hand joints. Initial manifestations may include fatigue, malaise, low-grade fever, and weight loss in some patients.⁴

Rheumatoid arthritis is a progressive disease that may lead to disability, which necessitates regular treatment and follow-up. Many factors such as chronic inflammatory pattern of pain, long duration of morning stiffness, development of hand deformities or dysfunctions as the disease

Received: March 17, 2017 **Accepted:** October 02, 2017 **Published online:** November 02, 2017

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progresses, nocturnal pain, and difficulty in mobility may cause these patients to become dependent on other people. In fact, patients with a history of onset of more than five years were reported to seriously need help from others, especially in household tasks.⁵ The people responsible for the care of patients are called caregivers, who undertake a very critical task for the patient due to the mentioned nature and characteristics of the disease. They also remain under pressure with the sustained course and ongoing requirements of the disease. All these factors challenge caregivers in many aspects such as physical and psychological strain, restriction in social life, and feeling of need for family support, disturbed sleep, financial problems, time constraint, and accompaniment of their own diseases, which collectively create an overloading on caregivers. RA has inflammatory and extraarticular systemic findings, long duration of morning stiffness and nighttime pain. Also, the cost of medicines that should be continuously used in RA is high.

Osteoarthritis (OA) is a chronic and disabling condition like RA, affecting approximately 13.9% of adults who are ≥ 25 years of age. The incidence of OA rises with age particularly in adults of ≥ 65 years of age. OA occurs more frequently in females, particularly in those older than 50 years of age.⁶ Both diseases are chronic, may cause disability and require regular follow-up; thus, a caregiver is needed for the follow-up of the patient and supplying of medicines. Rheumatoid arthritis sufferers are typically younger than those who develop OA, with RA occurring between 20 to 30 years of age, and the incidence peaking at 35 to 50 years of age. The incidence of RA is higher in females with a higher lifetime risk of 3.6% compared to males (1.7%).⁶⁻⁹

Therefore, in this study, we aimed to investigate the commitments and responsibilities of the family caregiver of RA patients and determine the association of these to the disease activity.

PATIENTS AND METHODS

The study was conducted at Firat University Faculty of Medicine Hospital and included a total of 240 subjects, consisting of 60 RA patients (8 males, 52 females; mean age 50.4 ± 11.1 years; range 25 to 76 years) whose diagnoses were established

upon American College of Rheumatology criteria between January 2010 and December 2012 with their 60 primary caregivers (42 males, 18 females; mean age 43.1 ± 15.3 years; range 12 to 77 years), and 60 OA patients (7 males, 53 females; mean age 62.8 ± 9.0 years; range 45 to 85 years) with their 60 primary caregivers (38 males, 22 females; mean age 47.6 ± 13.2 years; range 27 to 87 years). Questionnaires were applied to all patients and caregivers in a face-to-face setting. A comprehensive anamnesis was taken, followed by a clinical examination performed by the same physician. Sedimentation and C-reactive protein (CRP) values were recorded for each patient. The study protocol was approved by the Firat University Faculty of Medicine Ethics Committee. A written informed consent was obtained from each participant. The study was conducted in accordance with the principles of the Declaration of Helsinki.

Duration of disease, used medications and their durations, presence of concomitant diseases and their medications were questioned in RA and OA patients; additionally, extraarticular involvement was queried in RA patients. They were asked whether they were receiving or needed any special care or not. Degree of straining while performing their jobs, pain, patients' global assessment, self-reported rating of the ways their caregivers understand and support them were evaluated through visual analog scale (VAS). To interpret the VAS scale, for each parameter, patients and/or caregivers were asked for selecting points that were most appropriate for their condition on a 10 cm horizontal line. Patients and caregivers were asked to evaluate some questions separately using the VAS, i.e. we asked caregivers to answer questions such as "How many points do you give for the pain of the patient" and "Do you think the patient exaggerates his/her illness"?

Caregivers were asked to complete Caregiver Reaction Assessment (CRA) and Caregiver Strain Index (CSI) questionnaires. For measuring their objective responsibilities, duration of periods allocated for self-care (minute/day), household (hour/week), and assistance (hour/week) tasks were questioned.

Caregiver Reaction Assessment is a scale that was developed by Given et al.¹⁰ in 1992 in the United States to assess the care-related

overload on non-official caregivers who were family members of patients with chronic physical and/or mental impairment. This scale consists of 24 items under five domains, and evaluates both positive and negative reactions during giving care. Answers for each item are scored from 1 point to 5 points as following: 1 point=strongly disagree, 2 points=disagree, 3 points=neither disagree nor agree, 4 points=agree, and 5 points=strongly agree. In this questionnaire, there are five items under impact on schedule subscale, three items under impact on finances subscale, five items under lack of family support subscale, four items under impact on health subscale, and seven items under caregiver's esteem subscale. Higher scores of the latter subscale show higher caregiving burden, or vice versa. Cronbach alpha values of CRA equal to or above 0.7 indicate that the study is reliable.¹¹

Caregiver Strain Index was developed by Robinson in 1983 to identify problems encountered by family members who provide care to their ≥65-year-old patients undergoing heart or hip surgery.¹² Original version of CSI consisted of 13 items. While 10 of these items contain overall stress factors obtained from interviews with adult sons and daughters giving care to their parents, remaining three items consisted of potential risk factors identified through a literature search. All these items intend to question strain about

job, finance, physical, social, and allocated time issues. "Yes" corresponds to 1 point and "no" corresponds to 0 point. Total scores of ≥7 indicate high level of stress.

We also used the Western Ontario and McMaster Universities OA index, which is the most widely used disease-specific instrument for assessment of patients with OA.¹³

Statistical analysis

Statistical analysis was performed through PASW for Windows 18.0 version (SPSS Inc., Chicago, IL, USA) software. All values were presented as mean ± standard deviation. Groups were compared by one-way analysis of variance test, and post-hoc calculation normality test for the variables was performed by Tukey's test. Correlation analysis was determined by using Pearson correlation analysis. The value $p < 0.05$ was considered as statistically significant.

RESULTS

The socio-demographic characteristics of patients are shown in Table 1. While no RA patient had a private caregiver, only one OA patient had a private caregiver. All other caregivers were family members in both groups. Mean age of the

Table 1. Socio-demographic characteristics of patients

	Rheumatoid arthritis (n=60)				Osteoarthritis (n=60)			
	n	%	Mean±SD	Range	n	%	Mean±SD	Range
Age (year)			50.4±11.1	25-76			62.8±9.0	45-85
Disease duration (year)			10.9±9.0	0.5-37			8.3±5.7	1-30
Sex								
Females	52	86.7			53	88.3		
Males	8	13.3			7	11.7		
Private caregiver	0	0			1	1.66		
Marital status								
Married	55	91.7			46	76.7		
Single	3	5.0			14	23.3		
Widower	2	3.3			0	0		
Occupation								
Active	9	15			1	1.7		
Inactive	51	85			59	98.3		
Education level								
Illiterate	1	1.79			7	11.7		
Literate	1	1.7			4	6.7		
Primary school	19	31.7			10	16.7		
Middle school	9	15.0			9	15.0		
High school	18	30.0			15	25.0		
University	2	3.3			3	5.0		

SD: Standard deviation.

Table 2. Visual analog scale scores of rheumatoid arthritis patients and their caregivers

	RA patients (n=60)	RA caregivers (n=60)	p
	Mean±SD	Mean±SD	
VAS-pain (within last week)	57.0±34.4 (0-100)	80.6±228.3 (0-100)	0.432
VAS-pain (within last 6 months)	60.5±33.8 (0-100)	60.4±30.7 (0-100)	0.987
VAS-global assessment (within last week)	55.8±35.5 (0-100)	48.8±37.9 (0-100)	0.302
VAS-global assessment (within last 6 months)	56.5±33.6 (0-100)	58.5±33.0 (0-100)	0.733
VAS-caregiver support	17.5±28.1 (0-100)	16.9±23.6 (0-81)	0.902

RA: Rheumatoid arthritis; SD: Standard deviation; VAS: Visual analog scale; Significance was accepted if p value was below 0.05 at a confidence interval of 95%.

Table 3. Visual analog scale scores of osteoarthritis patients and their caregivers

	OA patients (n=60)	OA caregivers (n=60)	p
	Mean±SD	Mean±SD	
VAS-pain (within last week)	66.8±24.1 (0-100)	58.3±29.6 (0-100)	0.087
VAS-pain (within last 6 months)	55.8±26.1 (0-100)	52.7±28.0 (0-100)	0.526
VAS-global assessment (within last week)	63.6±25.8 (0-100)	57.5±31.6 (0-100)	0.251
VAS-global assessment (within last 6 months)	54.0±25.9 (0-100)	52.4±29.4 (0-100)	0.616
VAS-caregiver support	29.2±35.4 (0-97)	18.4±24.4 (0-81)	0.053

OA: Osteoarthritis; SD: Standard deviation; VAS: Visual analog scale; Significance was accepted if p value was below 0.05 at a confidence interval of 95%.

RA patients' caregivers was 43.1±15.3 years, which was statistically lower than the patients they cared (p=0.004). Mean duration of care provided was 10.3±9.1 years and 13.1±11.7 years in RA and OA patients, respectively.

According to VAS scores, majority of caregivers (77.4%) did not believe that their patients tended to exaggerate their illnesses. The percentage of caregivers who declared that they assisted their patients in their treatment, follow-up of the disease, and delivery of medications was 79.3%.

Table 2 summarizes VAS scores of RA patients and their caregivers. These two groups did not differ significantly in terms of VAS parameters.

No significant difference was detected between VAS scores of OA patients and their caregivers (Table 3).

Mixed results were obtained between the burden of caregiver and age in the study. There was a negative correlation between the age of the mildly activated patient's caregiver and VAS-caregiver score for "How much the patient exaggerated (r=0.851, p=0.007) his or her illness". On the other hand, there was no correlation between age and other parameters in moderately and highly activated patients.

Caregiver Reaction Assessment and CSI were applied to caregivers of RA and OA patients as

Table 4. Comparison of Caregiver Reaction Assessment, Caregiver Strain Index, and allocated time periods for objective responsibilities in caregivers of rheumatoid arthritis and osteoarthritis patients

	RA Caregiver (n=60)	OA Caregiver (n=60)	p
	Mean±SD	Mean±SD	
Caregiver reaction assessment-impact on schedule	15.8±4.5 (7-25)	15.2±4.0 (6-22)	0.482
Caregiver reaction assessment-impact on finance	9.6±3.4 (3-15)	8.4±3.4 (3-15)	0.052
Caregiver reaction assessment-lack of family support	12.1±4.2 (5-25)	11.6±4.5 (5-23)	0.562
Caregiver reaction assessment-impact on health	9.7±3.9 (4-20)	10.2±3.5 (4-18)	0.525
Caregiver reaction assessment-Caregiver's esteem	24.7±3.0 (18-32)	24.6±3.7 (16-33)	0.773
Caregiver Strain Index	5.1±3.3 (0-12)	5.2±3.3 (0-12)	0.784
Self-care tasks (min/day)	38.1±60.0 (0-300)	19.1±39.6 (0-180)	0.060
Household tasks (hour/week)	2.5±2.3 (0-10)	2.5±2.9 (0-15)	0.986
Assistance tasks (hour/week)	5.1±5.8 (0-40)	3.4±2.9 (0-12)	0.053

RA: Rheumatoid arthritis; OA: Osteoarthritis; SD: Standard deviation; Significance was accepted if p value was below 0.05 at a confidence interval of 95%.

Table 5. Correlation analysis between clinical parameters and disease activity score 28, sedimentation, C-reactive protein, morning stiffness in caregivers of rheumatoid arthritis and osteoarthritis patients

Parameters	DAS28	Sedimentation	CRP	MS
Caregiver reaction assessment-impact on schedule				
r	0.342	0.210	0.208	0.364
p	0.007	0.110	0.080	0.014
Caregiver reaction assessment-impact on finance				
r	0.273	0.01	0.003	0.124
p	0.035	0.994	0.980	0.418
Caregiver reaction assessment-lack of family support				
r	0.269	0.202	0.289	0.201
p	0.037	0.125	0.025	0.185
Caregiver reaction assessment-impact on health				
r	0.304	0.091	0.033	0.100
p	0.018	0.491	0.805	0.512
Caregiver reaction assessment-caregiver's esteem				
r	-0.77	-0.157	0.006	0.219
p	0.558	0.234	0.961	0.149
Caregiver Strain Index				
r	0.304	0.304	0.057	0.139
p	0.018	0.019	0.664	0.361
Self-care tasks (min/day)				
r	0.258	0.457	0.078	0.277
p	0.047	0.000	0.555	0.065
Household tasks (hour/week)				
r	0.224	0.185	0.282	0.062
p	0.085	0.162	0.029	0.688
Assistance tasks (hour/week)				
r	-0.280	-0.208	-0.071	-0.098
p	0.030	0.114	0.588	0.522

DAS28: Disease activity score 28; CRP: C-reactive protein; MS: Morning stiffness; *Significance was accepted if p value was below 0.05 at a confidence interval of 95%.

a subjective measure of straining during their caregiving. Cronbach alpha value of CRA was found as 0.70. Table 4 shows the comparison of CRA, CSI, and allocated time periods for objective task and responsibilities of RA and OA patients' caregivers.

A comparison of CRA and CSI scores, and allocated time periods for self-care and assistance tasks of caregivers of RA patients revealed statistically significant differences in impact on schedule, impact on finance, impact on health and lack of family support subscales of CRA. Table 5 shows the correlation analysis between the CRA, CSI, allocated time periods for self-care, household, assistance tasks and disease activity score 28 (DAS28), sedimentation, CRP, and morning stiffness in RA and OA patients' caregivers.

In our study, 36 of the 60 RA patients had comorbid diseases such as diabetes, heart

disorders, and chronic hypertension. VAS scores for "thinking that patient exaggerates his or her illness" ($p=0.09$) and CRA scores for financial problems ($p=0.047$) were statistically significant between caregivers of RA patients who had comorbid disease. In other words, caregivers of those with comorbid diseases thought that RA patients exaggerated their illness. Caregivers of these patients mentioned that they had more financial problems.

Of the 60 OA patients, 43 had comorbid diseases such as diabetes, heart disorders, and chronic hypertension. There was no statistically significant difference between caregivers of OA patients with or without comorbid disease.

DISCUSSION

Rheumatoid arthritis is chronic inflammatory condition that mainly affects joints of the patients

with an intermittent yet progressive course with flare-up and remission periods. This progressive nature of the disease results in irreversible damage to the joints, which in turn leads to minor disabilities, and consequently to physical, social, and psychological problems.¹⁴

During the course of the disease, functional impairments develop in RA patients. Ten-year follow-up studies reported severe disability-related strains in 10% of patients.¹⁵ In addition, their vitality and mobility are disturbed along with increased disease duration and pain. This results in dependence on surrounding people during daily indoor and outdoor activities.

Though the caregiver context was once used for those providing care for cancer patients, it became applicable for other patient groups as well. In particular, a multidimensional support including psychological, physical, mental, and emotional aspects is required in chronic diseases. Many RA patients need special care provided by non-professional caregivers especially at home. Slow and progressive course of the disease leads to long-term dependence on family members and friends. In fact, spouses or partners, in particular, desire sharing the majority of responsibility regarding caregiving. In our study, mean duration of disease of RA patients was 10.9 ± 9.0 years and we found that while 24 patients (40%) needed care, remaining 36 patients (60%) did not need care.

Caregiver Reaction Assessment is a questionnaire developed to evaluate the burden on people who provide care to chronic patients, consisting of usually family members.¹⁰ It measures positive and negative reactions of caregivers during giving care.¹⁶ So far, it has been translated into Dutch, English, German, Japanese, Korean, Norwegian, and Thai languages.¹⁷

The study by Jacobi et al.¹⁸ performed in RA patients and their caregivers reported that 25.6% of patients were receiving professional care whereas 6.9% were on the waiting list to receive such care. In our study, most caregivers were the spouses of the patients. No patient had any professional caregiver. Since professional care services are not a common feature of our society, main caregivers of our study population were patients' spouses or first degree relatives. In line with this, only one patient in the control group of OA patients had a professional caregiver.

For the objective assessment of caregivers of RA patients, they were asked whether or not they helped in certain tasks categorized as self-care, household, and assistance tasks. We found that increased disease activity led to increased assistance in shopping and accompaniment for health-related visits; in other words, patients became more dependent on the caregiver in daily life activities. When these findings were compared with OA patients' caregivers, no significant difference was detected. It is an interesting finding that the degree of reaction of OA patients' caregivers was similar to that of RA patients' caregivers except in helping with personal care, toilet care, and eating and drinking. Scores for these parameters were significantly higher in RA patients' caregivers. Impairment of hand functions and long-term morning detention may be the possible causes of this condition. Again, RA patients' caregivers were more likely to accompany patients in daily walking and sightseeing.

Tension, burden, and feeling of loneliness with depressive mood are common features of caregivers, particularly when they are family members of the affected individual. If untreated, these may lead to physical impairment and mental deterioration.¹⁹ When we analyzed the sharing of commitments and responsibilities of the patient by family members other than the caregiver using the lack of family support subscale of CRA, we did not find any significant difference between OA and RA patients' caregivers.

Several studies reported associations between burden on caregivers of RA patients and poor mental health conditions of both patients and caregivers, and between burden on caregivers and poor medical condition of patients, or arthritis-related poor symptom control, or their own deteriorated physical health.²⁰⁻²² In our study, we analyzed correlations by DAS28, CRP, sedimentation and morning stiffness and investigated if there was an association between disease activity and the burden on caregivers. There were significant differences in terms of impact on schedule, impact on finances and lack of family support on health subscales of the CRA. High disease activity group had significantly higher scores for these parameters. These findings suggest that impact on schedules, finances, lack of family support and health was higher in caregivers of patients with higher

disease activity ($p < 0.05$), (Table 5). Furthermore, there were significant differences between sedimentation and CSI and self-care tasks. The other positive correlation was found between CRP and house hold tasks and CRA-lack of family support. The other meaningful result was between morning stiffness and CRA score for impact on schedule.

A study by Jacobi et al.¹⁸ performed in 134 caregivers between 1997-2001 compared CRA subscales of caregivers of patients with RA, dementia, and colorectal cancers. While the level of self-esteem was similar between RA and cancer patients' caregivers, the other negative reaction parameters of CRA were as higher in cancer patients' caregivers. For the comparison of RA and dementia patients' caregivers, while diminution in self-care and physical strength was higher in RA, they were similar in terms of impact on schedule.²² In the present study, RA and OA patients' caregivers did not significantly differ in neither CRA and CSI parameters nor objective caregiving durations ($p > 0.005$), (Table 5).

Another study compared five subscales of CRA between caregivers of RA and stroke patients, and did not detect any significant difference.²³ In our study, we also failed to demonstrate any significant difference between OA and RA patients' caregivers in terms of the five subscales of CRA.

Comparison of CRA and CSI scores according to disease activity groups showed a significant difference in impact on schedule subscale of CRA ($p < 0.05$). In addition, impacts on health and finances were also significantly different, showing an increasing trend along with higher disease activity ($p < 0.05$). It appears inevitable that such impact on daily schedule of caregiver eventually results in stress and depression. Indeed, depression and stress disorder were reported among the leading psychosocial conditions observed in caregivers of RA.²⁴

Consistent with the current literature in terms of CRA,²⁵ main parameters of burden on caregivers in our study were financial impact, restriction in daily schedule, and lack of family support. The deterioration in these variables tends to increase parallel to the duration of care provided to the patient. In fact, certain issues such as financial and health problems were reported to increase among caregivers providing care for more than six hours

a day or for more than one year.²⁶ A United States study reported that the annual cost of RA patients was approximately 19.3 billion dollars, about 19% of which consisted of caregiver salaries.²⁷ Impact on finances encountered in caregivers of RA patients may be correlated with the development status of the country. For instance, a study in South Korea reported no impact on socioeconomic aspect among family member caregivers of RA patients, unlike our study.²⁴

Although we suggest that the burden of caregivers was associated with disease activity, it is possible that both factors may influence each other. Thus, larger controlled studies are required to validate that the caregiver's burden may affect disease activity. According to the literature, the relationship between disease activity and caregiver burden is not clear, while Yu et al.²⁸ concluded that the care recipient's cognitive status was directly associated with caregiver burden. On the other hand, Gonyea et al.²⁹ found no such direct relationship.

First limitation of our study was patient caregivers were not private caregivers. Most of them were family members. Second limitation was the small number of participants.

In conclusion, patient care is an important part of RA management, while chronic diseases create substantial burden on caregivers of patients. It should be kept in mind that impact on patient care may be associated with many patient- and caregiver-related factors. We believe that disease activity has a considerable impact on the commitments and responsibilities of individuals who primarily provide care for RA patients.

Declaration of conflicting interests

The authors declared no conflicts of interest with respect to the authorship and/or publication of this article.

Funding

The authors received no financial support for the research and/or authorship of this article.

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