

Determination of Correlation between Invalidation and Health Status in Patients with Rheumatoid Arthritis

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Abstract

Background: Patients with symptoms without any apparent signs suffer from a lack of understanding and support from others, which is called 'invalidation.' In rheumatoid arthritis (RA), some of the physical problems are often hidden, leading to a conflict, affecting the quality of life (QOL). We investigated the correlation between 'invalidation' of disease from other, with the QOL and symptom severity in RA patients.

Methods: In a cross- sectional study, 80 patients just diagnosed with RA – and without fibromyalgia criteria- entered the survey. To investigate invalidation, a questionnaire (Illness invalidation inventory) was used. Symptom severity of RA was measured by The Disease Activity Score28 (DAS28), and for Quality of life (QOL), the 12-item short-form (SF12) was used.

Results: The sense of being ignored by the spouse and family has the highest score (average: 35.5- 34.91, respectively) in patients with severe disease activity was the lowest (average: 15/73- 17.4, respectively) in patients with low disease activity, which was statistically significant ($P < 0.001$). The QOL had a significant negative correlation with the sense of being ignored by their spouse ($r = -0.84$), family ($r = -0.797$), and medical staff ($r = -0.414$), (All $P < 0.001$).

Conclusion: Patients with more severe RA experienced more neglect from their spouse, family, and employment. QOL fell considerably in individuals with greater DAS28 and was adversely connected with a sensation of being neglected by the spouse, family, and medical personnel. The overall degree of neglect in RA patients was high and was substantially connected to the patients' SF12 scores.

Keywords: Type Rheumatoid arthritis; neglecting; Invalidation; DAS28.

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1. Introduction

Rheumatoid arthritis (RA) is a chronic, systemic, and inflammatory disorder of unknown etiology, with symptoms such as multiple articular pain, swelling, morning stiffness, and fatigue. RA has various stages, often characterized by periods of exacerbation and sometimes remission. This disease's outcome varies, from silent to severe, leading to disability and even death in some patients. Without treatment, many patients will experience progressive joint destruction and significant disabilities[1]. The prevalence of RA is about 0.8 % of the population; in women is three times that of men, and its incidence increases with age[2]. Many studies contemplated a relationship between stress and RA flare and disease outcome [3-5]. Unfortunately, some symptoms of RA, such as chronic pain, stiffness, and fatigue, are invisible to others. In cases of lack of joint deformity, swelling, or laboratory findings, neglecting or misunderstanding the others may occur. This issue leads to a conflict of understanding between the patient, their partner, colleagues, and medical staff. This condition, recently recognized as 'invalidation', could be presented by neglecting the disease, lack of support, and perception from others of the primary illnesses[6, 7]. The sense of invalidation can be described as the perceptual and behavioral reactions of people around them, including denial, rhetoric, over-care, lack of emotional support, and rejection of symptoms [7]. Invalidation hurts mental health[8] and can intensify disease activity and physical disability [9]. Several studies have found that patients with such patience and friends have more stress, physical disease, and even higher mortality rates. Patients' rejection was associated with more somatic pain experiences [13, 14]. Also, these patients may hide their symptoms because of non-acceptance in family or society, which can influence an entire load of their useful life and the disease's consequence[15, 16].

According to social contract theory, observers usually look for credible evidence, such as clinical or pathological symptoms, because a person has to pay a fee (a real pain) to be able to receive the benefits (pity and help) [8]. When evidence is unavailable, people suspect that the patient wants to deceive others [9] and may underestimate the severity of the illness, so they will refuse to help the patient. This experience occurs as invalidation in patients. According to the above theory, medical professionals tend to underestimate the severity of the disease in the absence of obvious evidence of pain, such as swelling. They may sometimes suspect the patient of misinterpreting their illness [8, 10, 13]. Therefore, inconsistency in disease assessment occurs when symptoms of RA are intangible and non-perceptual, as well as inaccessible evidence such as organ dysfunction or laboratory abnormality[17]. Based on the available evidence, this theory may not be practical for the patient's partner and only seems reasonable to those around him, such as a community physician. The patient's partner is constantly evaluating the severity of the disease because these people interact with the patient daily and interact with one another in all aspects of life. The presence or absence of medical evidence will not affect the acceptability of the severity of pain and illness on the part of the patient's partner [14]. And sometimes, the patient's spouse may believe more than the patient's sense of pain [15, 16, 18-23]. Excessive overestimation can be destructive, as unbelievable as despair's sense of hopelessness. Because such behavior may be considered irrational empathy, RA patients suspect they are subjected to unpleasant situations such as being ordered, discredited, or over-monitored[18, 24]. Invalidation can have a detrimental effect on the patient's physical condition and psychological and social functioning. First, the induction of a sense of invalidation will not receive a favorable response from the community, whereas social support can improve the patient's health and relieve stress [25]. Secondly, invalidation exacerbates inappropriate community reactions and disapproval,

which can decrease and increase the sense of pain (via neural mechanisms) [26-29]. Third, to prevent unacceptability from the community, the patient may conceal or be isolated. These conditions may eventually result in undesirable interactions and awareness relationships amongst physicians. [30-32]. Previously used approaches to assessing unacceptability by the community would be impractical for intangible factors such as pain and fatigue. Also, the questionnaires used in previous studies did not apply to RA patients [33-35], so their susceptibility to invalidation varies. External factors, such as the patient's spouse, family, medical professionals, social factors, and colleagues, differ in the extent to which the patient is accepted or ignored [36]. Experiencing invalidation and reaction from family, friends, colleagues, and physicians may differ among rheumatologic diseases [18]. Many studies Investigated invalidation in fibromyalgia, but there is limited data about RA [19].

Using a questionnaire to assess invalidation can provide more insight into the experiences of RA patients and illustrate ways of investigating this phenomenon more closely [37]. RA affects various organs such as the joints, heart, lungs, mucosa, and brain. Fear of a chronic illness for all life and struggling with daily pain and disability would be highly distressing. Also, there is a close relationship between depression and rheumatoid arthritis. Recent research suggests that depression may be due to inflammation, which is common in arthritic rheumatism. It is unclear which is more likely effective, inflammation or the disease; however ever; both contribute to depression in some way [38-41]. The purpose of this study was to investigate the experiences of invalidation in RA patients. According to the current theory, invalidation has targeted mental functioning and lifestyle in the community rather than increasing the severity of the pain. The correlation between invalidation experienced by the spouse, family members, physicians, healthcare workers, coworkers, and social services with quality of life and severity of symptoms in patients with RA was evaluated.

2. Method

Precipitants were patients referred to the Rheumatology clinic of Hazrat-e-Rasool Hospital from January to December 2020. A rheumatologist diagnosed all patients using the 2010 ACR rheumatoid arthritis criteria [20]. Patients with overlap syndrome, fibromyalgia, other chronic diseases, and those under 18 years old were excluded. All demographic information containing age, sex, marital status, educational level, medication, and disease duration was documented. The consent form was obtained from all precipices, untenanted. The Ethical Committee approved the study at the Iran University of Medical Sciences.

2.1. Instrument

Invalidation was measured by the illness invalidation inventory (3*I) questionnaire [21]. We had used the Persian version of the 3*I questionnaire, which was translated to Persian and was validated by another expert[34]. It contains five items about discounting and three things about the lack of understanding, assessing the magnitude of invalidation patients experience by five resources (spouse, family, medical professionals, work environment, and social services). Disease activity was measured by the Disease Activity Score calculated on 28 joints (DAS28) [42]. Persian version of the SF-12 questionnaire has been used to assess physical and mental health status. Its validity and reliability have already been documented [40].

2.2. Statistical Analysis

All analyses were performed with SPSS 22.0 for the Windows version. Pearson correlation coefficient was used for correlation between quantitative variables. Spearman rank correlation was calculated for comparison between qualitative variables. Also, the Kruskal-Wallis H test was utilized for all univariate quantitative data. The significant level was set at $p < 0.05$.

3. Results

Eighty patients passed the inclusion/exclusion criteria and enrolled in this study. Men cases were 11 (13.7%) and female subjects were 69 (86.3%). The mean patients' age range was 44.5 (19 to 76 years, SD: 6.3). 18.8 % of precipitants had a higher education degree. The disease duration range was 1-31 years (mean: 9.82 years - SD: 6.83). Symptom severity based on DAS28 in 52.6% of patients was mild, 33.8 % moderate, and 13.8% severe.

The mean score of spouse neglect was highest in patients with severe RA (35.5) and was lowest in patients with mild RA (15.73), which was statistically significant ($P < 0.001$). (Table 1)

Table 1: Mean and standard deviation of spouse neglect based on the severity of RA disease

	The number of patients in each group who felt neglected	% of patients who were neglected, compared to all patients	Average scores of feeling neglected	Standard Deviation	P-value
mild	30	%71	15/73	3/503	<0/001
moderate	25	%92	28/32	4/470	
severe	8	%72	35/50	1/604	
Total	63	-	23/24	8/416	

The sense of family neglect was highest in severe RA (34.91) and lowest in patients with mild RA (17.4), which was statistically significant ($P < 0.001$). (Table 2)

Table 2: Mean and standard deviation of family neglect based on the severity of RA disease

	Number	Mean	Standard Deviation	P-value
Mild	42	17/40	5/831	<0/001
Moderate	27	27/56	4/309	
Severe	11	34/91	1/640	
Total	80	23/24	8/217	

But in the following cases, the severity of RA and the sense of being ignored did not show a statistically significant difference ($P > 0.05$), including Being ignored by medical staff - by colleagues - by employees of social and governmental organizations.

As shown in table 3 and figure 1, the mean and standard deviation of quality of life in patients with high severity of RA were significantly lower than in patients with mild severity (13.64 vs. 19.67) ($P < 0.001$). This difference was also observed in all subscales except for psychological problems and social functioning ($P < 0.05$).

Table 3: Mean and standard deviation of family neglect based on the severity of RA disease

SF-12	Severity	Numbers	Mean	Standard Deviation	P-value
Physical Performance	Mild	42	3/67	0/526	<0/001
	Moderate	27	2/48	0/509	
	Severe	11	2/18	0/405	
Physical Problems	Mild	42	3/21	0/782	<0/001
	Moderate	27	2/33	0/620	
	Severe	11	2/18	0/405	
Physical Pain	Mild	42	1/79	0/415	<0/001
	Moderate	27	1/37	0/492	
	Severe	11	1/09	0/302	
General Health	Mild	42	2/81	0/804	0/016
	Moderate	27	2/22	0/424	
	Severe	11	2/18	0/405	
Affect Problems	Mild	42	1/57	0/501	0/081
	Moderate	27	1/48	0/509	
	Severe	11	1/27	0/467	
Mental Health	Mild	42	3/43	0/630	<0/001
	Moderate	27	2/44	0/641	
	Severe	11	2/27	0/467	
Joy	Mild	42	1/60	0/497	0/016
	Moderate	27	1/37	0/492	
	Severe	11	1/18	0/405	
Social Performance	Mild	42	1/60	0/497	0/059
	Moderate	27	1/44	0/506	
	Severe	11	1/27	0/467	
Total Quality of Life Score	Mild	42	19/67	2/344	<0/001
	Moderate	27	15/15	1/680	
	Severe	11	13/64	1/502	

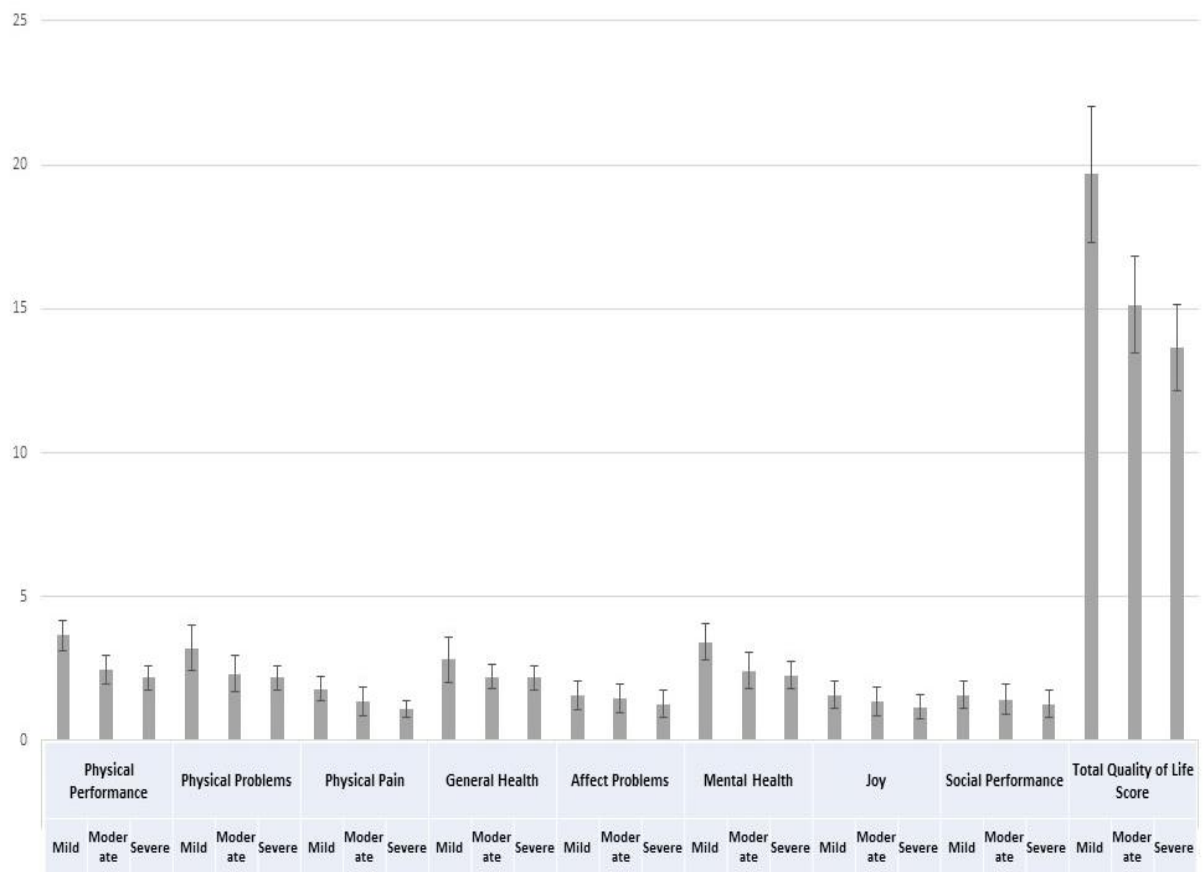


Figure 1: Mean and standard deviation of quality of life based on SF-12 based on the severity of RA

As can be seen in the table 4, patients' quality of life was neglected by their spouse ($r = -0.84$, $P < 0.001$), family ($r = 0.797$, $P < 0.001$) and medical staff ($r = -0.414$, $P < 0.001$). The two groups had a significant negative correlation ($P < 0.001$).

Table 4: Correlation between the studied variables

		Spouse	Family	Medical Stuff	Workplace	Social organization	Quality of Life	Severity of Disease
Spouse	Correlation Coefficient	1						
	Significance							
Family	Correlation Coefficient	.787**	1					
	Significance	Pvalue<0.001						
Medical Stuff	Correlation Coefficient	.334**	.406**	1				
	Significance	0.007	0					
Workplace	Correlation Coefficient	0.048	0.103	0.236	1			
	Significance	0.818	0.602	0.227				
Social organization	Correlation Coefficient	0.111	0.074	-0.009	.389*	1		
	Significance	0.388	0.512	0.935	0.04			
Quality of Life	Correlation Coefficient	-.840**	-.797**	-.414**	-0.082	-0.118	1	
	Significance	0	0	0	0.679	0.299		
Severity of Disease	Correlation Coefficient	.886**	.798**	0.204	0.02	0.192	-.756**	1
	Significance	0	0	0.069	0.918	0.088	0	

** . P< 0.01 level (2-tailed) * . P< 0.05 level (2-tailed)

4. Discussion

RA is a chronic, systemic, and inflammatory disorder of unknown etiology that affects the joints, heart and lungs, kidneys, mucosa, and the brain[17]. Some of these symptoms may be hidden, which leads to negligence and invalidation of patients, which affects their quality of life [31].

This study aimed to measure the relationship between invalidation and RA patients' severity and quality of life.

Of the 80 patients included in the study, 42 (52.5%) had mild RA, 27 (33.8%) had moderate, and 11 (13.8%) had severe RA. The feeling of being ignored by the spouse had the highest score (35.5) in patients with severe RA and the lowest score in patients with mild RA (15.73), which was significantly different. Also, the sense of being ignored by the family was the highest (34.91) in patients with severe RA and the lowest (17.4) in patients with mild RA, which was statistically significant.

It was found that the mean and standard deviation of quality of life in patients with high severity of RA were significantly lower than in patients with mild severity (13.64 vs. 19.67), and this difference was significant across all subscales except for mental health and social functioning. It was also seen.

But, there was no statistically significant difference between the mean and standard deviation of the feeling of being ignored by medical professionals, colleagues, and employees of social and governmental organizations based on the severity of RA.

Finally, it was found that patients' quality of life was significantly negative correlation with feelings of being ignored by their spouse ($r = -0.84$, $P < 0.001$), family ($r = -0.797$, $P < 0.001$) and medical staff ($r = -0.414$, $P < 0.001$).

The relationship between invalidation and the clinical situation, mental health, and personality traits of the patients was studied by Marina Santiago and his colleagues (2017). With a sample size of 124 cases, a 10-item I-3 Questionnaire and multiple analyzes were used. The analysis showed a correlation between the mentioned variables and invalidation [31]. Our study also found that the severity of the disease in patients with RA was significantly associated with a sense of being neglected. An increased feeling of being ignored led to a decreased quality of life.

The relationship between social support and family members' performance with RA patients was investigated by Mary Coty and Kate Wallston (2010). In 73 patients, their results showed a correlation between symptoms of RA disease and inappropriate social support ($P < 0.0001$) and family members' performance ($P < 0.001$). There was a significant relationship between patient satisfaction and lack of depressive symptoms ($P < 0.001$) [41]. That results align with our study findings on the severity of RA disease, inappropriate social support, and family members' performance. But in our study, it was found that inadequate support can reduce the sociopatients' social and family function, quality of life, and satisfaction of patients.

In another study by Marian Kool (2012), the sense of loneliness, the lack of social support, and its association with invalidation were investigated. In 171 RA and 341 FM patients, questionnaires of 11-point Likert score assessing loneliness, the I-3 questionnaires, and the Social Support Questionnaire (SSS) were used. RA patients experienced more loneliness based to this study. It concluded that to diminish the sense of loneliness and increase the social support of those patients, more attention should be paid to them [38]. Our study also found that the severity of the disease in patients with RA was significantly associated with a sense of being neglected, and an increase in the feeling of being ignored led to a decrease in the quality of life in patients, too.

But how invalidation and social support were linked to RA patients' mental and physical health; Kool and his colleagues (2013) surveyed this question. Totally 1455 patients participated in their online questionnaire. Based on the results, invalidation and social support were integrated with the patient's mental health. However, for symptoms of invalidation, only discounting was significantly associated with the patient's physical health. Therefore, to improve the psychological and physical conditions of rheumatic patients, invalidation and social support should be managed in an integrated manner [43]. The results of this study are in line with the findings of our research. We found that patients' quality of life was negatively correlated with feelings of being ignored by their spouse, family, and medical staff.

In another study conducted by Kool and his colleagues (2011), they examined how a patient's spouse evaluated the RA disease in their partner and the relationship between the sense of invalidation and its inconsistency with the patient's experience. The SF-20 and I-3 questionnaires were used, and 95 FM and 86 RA patients participated. Based on the results, the spouses' evaluation of the condition and symptoms of FM patients was significantly higher than that of RA patients. The discrepancy between the patient's mate's perceptions did not correlate substantially with invalidation.

Based on the results of that study, invalidation by the patient's partner did not correlate with the presence or absence of medical documentary evidence of the disease [38]. However, in our study, it was found that the feeling of being ignored by the spouse was the highest (35.5) in patients with severe RA and was the least in patients with mild RA (15/73), and the difference was statistically significant. This may be due to differences in sample size, demographic characteristics of patients, inclusion and exclusion criteria, confounding effects, type of questionnaires, and differences in affective conditions, especially duration of illness.

Also, in a study by Kool and his colleagues (2010) on RA patients to validate the I-3 questionnaire, 142 RA patients and 167 FM patients participated. The discounting and misunderstanding of FM patients have shown a more devastating impact. Both patients experienced a sense of invalidation from others, including family members, medical professionals, colleagues, and spouses. Thus, discounting and misunderstanding led to a decrease in the mental health of these patients, and there was more discounting in RA patients than in FM patients [13]. The results of this study are compatible with the findings of our research. Our survey also found that the severity of the disease in patients with RA was significantly associated with a sense of being neglected, and an increase in the feeling of being ignored led to a decrease in the quality of life in patients.

5. Conclusion

Our study showed that patients with higher disease activity had a higher score of being ignored by their spouse, family, and workplace. It was also found that the quality of life of patients with severe RA decreased significantly. The quality of life was negatively correlated with feelings of being ignored by the spouse, family, and medical staff. Therefore, based on the results, it can be concluded that the feeling of being overlooked in patients with RA is high, and this issue is directly related to the quality of life of these patients. Accordingly, proper education to the family and psychological assistance of patients to cope with the illness and restrict control of RA reduce the feeling of being ignored and enhance patients' quality of **life**.

6. Offers

Based on the results of the present study and other studies, which indicate a high level of neglect in these patients, as well as its association with the severity of RA disease, the following items are suggested:

1. Regularly review positive signs and symptoms, clinical examination, and paraclinical evaluations. It can help to timely identify RA patients with a sense of being overlooked and provide faster counseling services.
2. Conducting meetings and providing information to patients' families to improve their awareness of patients' situations.
3. Considering the importance of managing this disease and the small number of currently available studies, further surveys with larger sample size and systematic or prospective studies are recommended.

Reference

- [1]. Zielinski, M.R., D.M. Systrom, and N.R. Rose, Fatigue, Sleep, and Autoimmune and Related Disorders. *Frontiers in Immunology*, 2019. 10(1827).
- [2]. Almutairi, K., et al., The global prevalence of rheumatoid arthritis: a meta-analysis based on a systematic review. *Rheumatology International*, 2020.
- [3]. Hassett, A.L. and D.J. Clauw, The role of stress in rheumatic diseases. *Arthritis research & therapy*, 2010. 12(3): p. 123-123.
- [4]. de Brouwer, S.J., et al., Experimental stress in inflammatory rheumatic diseases: a review of psychophysiological stress responses. *Arthritis Res Ther*, 2010. 12(3): p. R89.
- [5]. Kojima, M., et al., Depression, inflammation, and pain in patients with rheumatoid arthritis. *Arthritis Rheum*, 2009. 61(8): p. 1018-24.
- [6]. Lwin, M.N., et al., Rheumatoid Arthritis: The Impact of Mental Health on Disease: A Narrative Review. *Rheumatol Ther*, 2020.
- [7]. Szady, P., G. Bączyk, and K. Kozłowska, Fatigue and sleep quality in rheumatoid arthritis patients during hospital admission. *Reumatologia*, 2017. 55(2): p. 65-72.
- [8]. Heidari, B., Rheumatoid Arthritis: Early diagnosis and treatment outcomes. *Caspian J Intern Med*, 2011. 2(1): p. 161-70.
- [9]. Machado-Alba, J.E., A.F. Ruiz, and D.A. Medina Morales, The epidemiology of rheumatoid arthritis in a cohort of Colombian patients. *Revista Colombiana de Reumatología*, 2015. 22: p. 148-152.
- [10]. Sturgeon, J.A., P.H. Finan, and A.J. Zautra, Affective disturbance in rheumatoid arthritis: psychological and disease-related pathways. *Nat Rev Rheumatol*, 2016. 12(9): p. 532-42.
- [11]. Toye, F., K. Seers, and K.L. Barker, Living life precariously with rheumatoid arthritis - a mega-ethnography of nine qualitative evidence syntheses. *BMC Rheumatol*, 2019. 3: p. 5.
- [12]. Spaeth, M., Fibromyalgia - a challenge for health care systems or: don't leave the physician out in the cold. *Clin Exp Rheumatol*, 2010. 28(6 Suppl 63): p. S1-2.
- [13]. Kool, M.B., et al., Lack of understanding in fibromyalgia and rheumatoid arthritis: the Illness

- Invalidation Inventory (3*I). *Ann Rheum Dis*, 2010. 69(11): p. 1990-5.
- [14]. Kappesser, J., A.C. Williams, and K.M. Prkachin, Testing two accounts of pain underestimation. *Pain*, 2006. 124(1-2): p. 109-16.
- [15]. Maafi, A.A., et al., Serum Vitamin D Status in Iranian Fibromyalgia Patients: according to the Symptom Severity and Illness Invalidation. *Korean J Pain*, 2016. 29(3): p. 172-8.
- [16]. Schulz, R. and P.R. Sherwood, Physical and mental health effects of family caregiving. *Am J Nurs*, 2008. 108(9 Suppl): p. 23-7; quiz 27.
- [17]. Turesson, C., et al., Extra-articular disease manifestations in rheumatoid arthritis: incidence trends and risk factors over 46 years. *Annals of the Rheumatic Diseases*, 2003. 62(8): p. 722.
- [18]. Eisenberger, N.I., et al., An experimental study of shared sensitivity to physical pain and social rejection. *Pain*, 2006. 126(1-3): p. 132-8.
- [19]. Arnold, L.M., et al., Patient perspectives on the impact of fibromyalgia. *Patient Educ Couns*, 2008. 73(1): p. 114-20.
- [20]. Edwards, T.M., et al., The treatment of patients with medically unexplained symptoms in primary care: a literature review. *Ment Health Fam Med*, 2010. 7(4): p. 209-21.
- [21]. Sulmasy, L.S. and T.A. Bledsoe, American College of Physicians Ethics Manual. *Annals of Internal Medicine*, 2019. 170(2_Supplement): p. S1-S32.
- [22]. Kappesser, J. and C.W.A.C. de, Pain judgments of patients' relatives: examining the use of social contract theory as a theoretical framework. *J Behav Med*, 2008. 31(4): p. 309-17.
- [23]. Cano, A., A.B. Johansen, and M. Geisser, Spousal congruence on disability, pain, and spouse responses to pain. *Pain*, 2004. 109(3): p. 258-65.
- [24]. Kappesser, J. and A.C. Williams, Pain estimation: asking the right questions. *Pain*, 2010. 148(2): p. 184-7.
- [25]. Martire, L.M., et al., Older spouses' perceptions of partners' chronic arthritis pain: implications for spousal responses, support provision, and caregiving experiences. *Psychol Aging*, 2006. 21(2): p. 222-230.
- [26]. Lehman, A.J. et al., Do spouses know how much fatigue, pain, and physical limitation their partners with rheumatoid arthritis experience? Implications for social support. *Arthritis Care Res (Hoboken)*, 2011. 63(1): p. 120-7.
- [27]. Ozbay, F., et al., Social support and resilience to stress: from neurobiology to clinical practice. *Psychiatry (Edgmont)*, 2007. 4(5): p. 35-40.
- [28]. Eisenberger, N.I. and M.D. Lieberman, Why rejection hurts: a common neural alarm system for physical and social pain. *Trends Cogn Sci*, 2004. 8(7): p. 294-300.
- [29]. Glasgow, R.E., et al., A social-ecologic approach to assessing support for disease self-management: the Chronic Illness Resources Survey. *J Behav Med*, 2000. 23(6): p. 559-83.
- [30]. Kool, M.B. et al., Understanding the lack of understanding: invalidation from the perspective of the patient with fibromyalgia. *Arthritis Rheum*, 2009. 61(12): p. 1650-6.
- [31]. Santiago, M.G., et al., Invalidation in Patients with Rheumatic Diseases: Clinical and Psychological Framework. *J Rheumatol*, 2017. 44(4): p. 512-518.
- [32]. Ghavidel-Parsa, B., et al., The Iceberg Nature of Fibromyalgia Burden: The Clinical and Economic

- Aspects. *Korean J Pain*, 2015. 28(3): p. 169-76.
- [33]. Bidari, A., B. Ghavidel Parsa, and B. Ghalehbaghi, Challenges in fibromyalgia diagnosis: from the meaning of symptoms to fibromyalgia labeling. *Korean J Pain*, 2018. 31(3): p. 147-154.
- [34]. Ghavidel-Parsa, B., et al., Correlation of invalidation with symptom severity and health status in fibromyalgia. *Rheumatology*, 2014. 54(3): p. 482-486.
- [35]. Carville, S.F., et al., EULAR evidence-based recommendations for the management of fibromyalgia syndrome. *Ann Rheum Dis*, 2008. 67(4): p. 536-41.
- [36]. Dueñas, M., et al., A review of chronic pain impact on patients, their social environment and the health care system. *J Pain Res*, 2016. 9: p. 457-67.
- [37]. Margaretten, M., et al., Depression in patients with rheumatoid arthritis: description, causes, and mechanisms. *Int J Clin Rheumtol*, 2011. 6(6): p. 617-623.
- [38]. Kool, M.B., et al., Patient and spouse appraisals of health status in rheumatoid arthritis and fibromyalgia: discrepancies and associations with invalidation. *Clin Exp Rheumatol*, 2011. 29(6 Suppl 69): p. S63-9.
- [39]. Redinbaugh, E.M., et al., Factors associated with the accuracy of family caregiver estimates of patient pain. *J Pain Symptom Manage*, 2002. 23(1): p. 31-8.
- [40]. Montazeri, A., et al., The Iranian version of 12-item Short-Form Health Survey (SF-12): factor structure, internal consistency and construct validity. *BMC Public Health*, 2009. 9: p. 341.
- [41]. Coty, M.B. and K.A. Wallston, Problematic social support, family functioning, and subjective well-being in women with rheumatoid arthritis. *Women Health*, 2010. 50(1): p. 53-70.
- [42]. Prevoo, M.L., et al., Modified disease activity scores that include twenty-eight-joint counts. Development and validation in a prospective longitudinal study of patients with rheumatoid arthritis. *Arthritis Rheum*, 1995. 38(1): p. 44-8.
- [43]. Kool, M.B. et al., Social support and invalidation by others contribute uniquely to the understanding of physical and mental health of patients with rheumatic diseases. *J Health Psychol*, 2013. 18(1): p. 86-95.