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RESEARCH PAPER

Social support and psychological distress in rheumatoid arthritis: a 4-year prospective study

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Introduction: The objective of the study was to investigate the course of psychological distress in early rheumatoid arthritis patients and to explore the strength of its associations with disease-related variables over time. A further aim focused specifically on the associations between social support and psychological distress. **Methods:** The study had a longitudinal design, with four annual measurements over consecutive years. The course and stability of psychological distress on the individual level were investigated via test–retest correlation coefficients and changes over time were studied using the Friedman test for repeated measurements. Hierarchical regression analysis was performed to analyze the multilinear associations of disease activity, functional disability, joint tenderness, pain and social support with psychological distress. **Results:** Significant cross-sectional associations were found among functional disability, joint tenderness, pain, emotional support, instrumental support and psychological distress. However, after controlling for the erratic pattern of the disease and the relevant variables, only initial psychological distress and emotional support retained a significant relationship with psychological distress. The final regression model, in which functional disability, pain, emotional support and initial psychological distress were significant variables, explained 36% of the variance in psychological distress. **Conclusion:** The study stresses the importance of initial psychological distress, which was found to have the highest correlation with psychological distress experienced 4 years later. In addition, higher emotional support and lower pain were found to be the only variables independently associated with lower levels of psychological distress after controlling for the relevant variables.

Implications for Rehabilitation

- Psychological distress is a relevant problem in rheumatoid arthritis patients and should be recognized early in the disease as it might reflect a lack of social resources which can be crucial in the further course of the disease.
- Special attention should be paid to different types of social support in relation to psychological distress, which might improve targeting psychosocial interventions.

Keywords: Functional disability, pain, psychological distress, psychosocial, rheumatoid arthritis, social support

Introduction

Rheumatoid arthritis (RA) is a chronic progressive autoimmune disease of unknown etiology. It is characterized by joint inflammation, great pain, stiffness, tiredness, deformities and physical impairment, which often leads to functional disability and threatens the ability to perform regular daily activities [1,2]. RA is accompanied by frequent flare-ups and remissions which form an unpredictable course of disease activity and elicit feelings of uncertainty about the future [3]. As with other chronic diseases, these biologically and psychologically based effects cause problems in different areas of life by, for example, reducing or restricting a patient's ability to work or perform different tasks. This may subsequently lead to the loss of valued activities and may cause problems in

performing social roles, all of which has a great impact on a patient's psychological functioning [4,5]. Due to the nature of the disease and especially its erratic pattern [6], longitudinal studies have been carried out and are still required to investigate and clarify the impact of RA [7,8].

RA patients have been found to frequently experience psychological distress (anxiety and depression). Several studies have found elevated levels of depression and anxiety in patients with RA in comparison with healthy controls [9–11]. A close association among pain, functional disability and psychological distress has been suggested by a number of authors [12,13]. Especially pain has been found to be closely associated with psychological distress and with depression in particular. Many studies focusing on depression and pain have shown a strong and stable association between chronic pain and symptoms of depression in RA as well as in other chronic pain disorders [15–17]. However, recent studies have also found considerable evidence that psychosocial variables and especially stressors from the social environment can increase vulnerability to episodes of pain and disturbances in mood among patients with chronic conditions such as RA [18,19].

Nevertheless, individual differences in psychological mood cannot be fully explained by variations in disease status, and thus other explanatory variables are needed [3,20]. Given that the presence of psychological distress may not be solely related to the activity-limiting and disabling effect of arthritis, it may reflect the lack of social support and experience of social stress to which these patients are often exposed [19,21]. Moreover, factors such as social isolation, partly caused by increasing functional disability as well as exposure to social stress may increase the risk of elevated levels of psychological distress even in patients with less severe RA [22].

The overall benefits of social support on well-being have been well recognized and documented in the general population as well as among people with various chronic diseases [19,23–25]. Nevertheless, it must be emphasized that social support is a multi-dimensional phenomenon and a number of studies have explored its facets and its specific functions [7,14,26]. Furthermore, an important distinction has to be made in cases where social support can be addressed either as a structure reflecting one's rootedness in the social system or from a functional point of view [27]. According to Cohen [28], it is essential when exploring social support that the type of the support reflects the needs of the situation. Successful adaptation to a chronic disease like RA requires support from different resources, among which help from others is very important [29]. Functional disability affects the performance of daily activities, and a lack of external help may threaten the independence of patients. Thus, successful adaptation is closely connected to the availability of social support [30]. Focusing on psychological distress, we consider two aspects of social support in particular as highly relevant for this study. These are practical aid, defined as instrumental support, and emotional sustenance, defined as emotional support.

Studies addressing the problem of social support tend to focus on and emphasize the positive effects of interpersonal ties, whether in their structural or functional dimension [31–33]. In contrast, other authors argue that close

relationships can be supportive and caring but that they can also be characterized by misunderstanding, disapproval and antagonism, depending on the fit between the function of the social support type and the patient need [7,14,34]. Therefore, it is very important that the approach also reflects the qualitative aspects of the support provided. For example, Doeglas [14] found that satisfaction with social support is more closely related to patient's well-being than the actual amount of social support. Keeping this in mind, the subjective evaluation of support can be just as important as the amount of support received, because social support provided to the patient may be less than needed, sufficient or too much, depending on the needs and characteristics of the patient [35].

Therefore, based on the aforementioned, the aim of our study was two-fold. First, by taking advantage of the longitudinal design, the objective was to investigate the course of psychological distress and its stability or fluctuation in RA patients and to explore the strength and direction of its associations with disease activity, functional disability, joint tenderness and pain as markers of the disease over time. Second, the aim focused specifically on the associations between social support and psychological distress.

Methods

Sample and procedure

This study is a part of the European Research on Incapacitating Diseases and Social Support study (EURIDISS) [36]. Four waves (T1–T4) of data collection were carried out. Inclusion criteria for participating in the study were as follows: age from 20 to 70 years at the beginning of the study; RA diagnosed no more than 4 years before the beginning of the study; fulfillment of at least four criteria of the American College of Rheumatology [37]; and signing of the informed consent form. Exclusion criteria were the presence of another physical handicap, the presence of another chronic disease (comorbidity), malignant RA, or any other identified reason for potentially dropping out of the study in the future.

Before the start of the study, all patients from the outpatient clinics in the two largest cities in eastern Slovakia, Prešov and Košice, who at that time met the above-mentioned required criteria, were identified. One hundred and seventy-six patients were found suitable for the study and were approached by their rheumatologists. Of the 176 approached people with RA, 116 (72.5%) participated in all waves and provided complete data for present analysis (Figure 1). The dropouts and patients participating in the fourth wave were compared to find out whether they differed in characteristics obtained at the beginning of the study. Disease duration in months, age, disease severity measured by Steinbrocker scale [39] and sex were explored, and no significant differences were found.

Data were collected via a structured interview lasting about 90 minutes conducted by a trained interviewer. Patients were also asked to fill in self-report questionnaires, and a rheumatologist performed a medical examination. Additional information was retrieved from patient medical files. The study was approved by the local ethics committee of the PJ Safarik University in Kosice.

Figure 1. The pattern of initial recruitment, loss to follow-up and exclusion of participants in the study sample.

Measures

Joint tenderness

Joint tenderness was assessed using the Ritchie Articular Index (RAI). This examination was performed by a rheumatologist as a part of the medical examination. Firm pressure to each joint was applied and the patient's reaction was recorded on a five-point scale ranging from "no pain," "pain complaint," "complaint and wince," "complaint wince" to "withdrawal" [40].

Disease activity

Disease activity was assessed using the erythrocyte sedimentation rate (ESR) after the first hour, which is routinely used as an indicator of disease activity.

Pain

Pain was measured using the subscale of the Nottingham Health Profile (NHP), a generic self-report measure. The pain subscale contains eight items referring to the experience of pain. Each item can be answered either yes or no, with a theoretical range of 8–16. The sum of all answers creates the total score [41]. The measure has been explored for psychometric properties regarding reliability and validity against other

frequent pain measures among Slovak RA patients and has had satisfactory results [42,43]. Cronbach's α at the baseline of the study was 0.82 for this scale.

Functional disability

Functional disability was measured using the Health Assessment Questionnaire. It is a self-report questionnaire frequently used in RA research. Respective items reflect activities of daily life, and respondents indicate how much difficulty they have in performing these activities on a four-point scale ranging from "without difficulty" to "unable to do," with a theoretical range of 0–3 [37,38]. The scale generally demonstrates very good psychometric properties and is commonly used to assess functional disability in RA populations [44]. Cronbach's α in this study assessed at the baseline was 0.80.

Social support

Social support was measured by the Satisfaction with Social Support Questionnaire (SSQS) developed by Doeglas et al. [45]. In our study, two subscales from this measure were used to assess satisfaction with emotional support (ESS) and satisfaction with instrumental support (INS). The measure was originally designed within the EURIDISS project to address the very detailed structure of social support transactions. The following studies using SSQS identified emotional and instrumental type of support as the most relevant in relation to psychological distress [14,35]. Within this instrument, the discrepancy between the received and the desired amount of social support was considered to be the indicator of satisfaction with the social support. Each item was asked twice. First, the patients were asked whether certain supporting transactions had occurred and how often; second, they were asked how satisfied they had been with the number of these transactions. The patients answered each question on a three-point Likert-type scale (1–3), with a higher score indicating more satisfaction with supportive transactions [27]. The theoretical range was 11–33 for ESS and 7–21 for INS. Cronbach's α in this study was 0.86 for ESS and 0.76 for INS at the baseline.

Psychological distress

Psychological distress was indicated by subscales of depression and anxiety from the General Health Questionnaire (GHQ-28) developed by Goldberg [46]. The patient is asked to compare his recent health status with his usual health status and to answer each question on a four-point Likert-type scale. The scale has been frequently used in RA populations and has demonstrated good psychometric properties [2,26]. As suggested by Strating [6], subscales of anxiety and depression were combined into one single 14-item scale to measure the amount of psychological distress, with a possible range of 14–56. A higher score indicates a higher level of psychological distress. This scale was previously used in the Slovak part of the EURIDISS project and demonstrated satisfactory psychometric characteristics in samples of Slovak patients [47]. Cronbach's α for this combined scale was 0.83 at the baseline.

Statistical methods

Descriptive statistics were first calculated for all study variables. The course and stability of psychological distress at the

Table I. People with early rheumatoid arthritis at baseline and follow-up (n = 116).

		T1	T2	T3	T4	Friedman test	
	Range of scores	Baseline	12 months	24 months	36 months	p value	
1	Sex (% female)	84.5%					
2	Age	47.59 (12.35)					
3	Married (%)	77.6%					
4	Disease duration	22.13 (16.09)					
5	ESR	0–150	26.25(18.11)	22.86 (17.65)	23.09 (17.79)	26.02 (18.09)	ns
6	GHQ (distress)	14–56	24.79 (7.00)	23.21 (6.67)	23.44 (6.73)	24.48 (8.10)	ns
7	HAQ	0–3	1.15 (0.68)	1.08 (0.66)	1.05 (0.72)	0.98 (0.74)	ns
8	RAI	0–72	13.46 (7.41)	13.09 (9.26)	12.45 (9.47)	11.48 (9.02)	0.003
9	NHP (pain)	8–16	11.16 (2.55)	11.70 (2.72)	11.45 (2.52)	11.38 (2.66)	ns
10	ESS	11–33	29.52 (4.07)	30.24 (3.57)	30.70 (3.51)	30.72(3.78)	0.000
11	INS	7–21	19.34 (2.53)	19.75 (2.38)	19.60 (2.60)	19.76 (2.68)	0.003

ESR, erythrocyte sedimentation rate; ESS, emotional support satisfaction; GHQ, General Health Questionnaire; HAQ, Health Assessment Questionnaire; INS, Instrumental Support Satisfaction; NHP, Nottingham Health Profile; ns, not significant; RAI, Ritchie Articular Index.

Note: Higher scores indicate more psychological distress, more functional disability, more tender joints, less pain, more satisfaction with emotional support and more satisfaction with instrumental social support.

individual level were investigated via test–retest Spearman correlations. Changes over time indicating differences at the group level were studied using the Friedman test for repeated measurements. Associations among ESR, joint tenderness, pain, functional disability and psychological distress over time were studied using cross-sectional Spearman's ρ correlations. Finally, hierarchical regression analysis was performed to investigate the predictive value of ESR, joint tenderness, pain, functional disability and social support on psychological distress.

To reduce the variations between measurement times, a summary measure was calculated for all independent variables serving as predictors prior to performing hierarchical regression analysis. To predict psychological distress at T4, the scores of the independent variables (joint tenderness, pain, functional disability, ESS and INS) at T1, T2 and T3 were summed and divided by 3. The proposed method of analysing data has been used before to avoid fluctuating levels in study variables and it has also been applied in the context of RA [6,48]. All data were analyzed using SPSS (version 14, SPSS Inc., Chicago, IL, USA).

Results

The distribution of sex and marital status, as well as the means and the standard deviations for age, disease duration, ESR, joint tenderness, pain, functional disability, social support measures and psychological distress, is displayed in Table I.

Psychological distress remained fairly stable over time, and no significant differences were found at the group level when the four consecutive measurements were compared. Test–retest Spearman's ρ correlations of psychological distress between consecutive measurements demonstrated significant associations (from $\rho = 0.52$ to $\rho = 0.63$, all $p \leq 0.001$).

With regard to ESR, pain and functional disability, the Friedman test did not reveal any significant differences over time. Joint tenderness showed a slight decreasing tendency ($\chi^2_3 = 14.3$, $p \leq 0.01$). The social support measures (emotional and instrumental) generally showed a gradual increasing tendency, a trend confirmed as statistically significant ($\chi^2_3 = 14.5$, $p \leq 0.001$; $\chi^2_3 = 18.3$, $p \leq 0.01$).

Table II. Cross-sectional correlations between study variables and psychological distress across four waves in people with rheumatoid arthritis (Spearman's ρ).

	GHQ (distress) T1	GHQ (distress) T2	GHQ (distress) T3	GHQ (distress) T4
HAQ	0.16	0.21*	0.22**	0.32**
RAI	0.23*	0.19*	0.18	0.32**
NHP (pain)	−0.30**	−0.47***	−0.43**	−0.54**
ESS	−0.21*	−0.32**	−0.22**	−0.34**
INS	−0.26*	−0.19*	−0.20**	−0.24**

ESS, emotional support satisfaction; GHQ, General Health Questionnaire; HAQ, Health Assessment Questionnaire; INS, Instrumental Support Satisfaction; NHP, Nottingham Health Profile; RAI, Ritchie Articular Index.

** $p < 0.01$; * $p < 0.05$.

Cross-sectional correlations

Cross-sectional correlations were performed in the next step in order to investigate the associations of ESR, joint tenderness, pain, functional disability with psychological distress (Table II). ESR was not correlated with psychological distress at any point in time. Joint tenderness showed the highest correlation with psychological distress at T4 ($\rho = 0.32$, $p < 0.01$). Pain showed a significant correlation with psychological distress at every point of measurement ($\rho = -0.30$ at T1 to $\rho = -0.54$ at T4, both $p \leq 0.01$). Similarly, functional disability gradually became correlated with psychological distress, appearing insignificant at T1 but significant at subsequent waves (T2: $\rho = 0.21$, $p \leq 0.05$; T3: $\rho = 0.22$, $p \leq 0.01$; T4: $\rho = 0.32$, $p \leq 0.01$). Social support measures showed low significant correlations with psychological distress (from $\rho = -0.19$, $p \leq 0.01$ to $\rho = -0.34$, $p \leq 0.01$). Overall, cross-sectional analysis showed that the association among the disease variables represented by joint tenderness, pain, functional disability and psychological distress was strongest in the fourth wave.

Before hierarchical regression was performed, the mean scores from the first three measurements (T1, T2, T3) were calculated for every independent variable, and the Spearman's ρ correlation coefficients were computed. These are displayed in Table III. Significant correlations were found between all independent variables chosen as predictors and psychological distress at T4 as the criterion variable. Sociodemographic variables and disease duration did not show any significant

associations with psychological distress. Nevertheless, they were not omitted from the latter analysis and were controlled.

Hierarchical regression analysis

After a correlation analysis of all the variables included into the hierarchical regression, an analysis was performed to identify which variables would serve as reliable predictors of psychological distress at T4. This was particularly with regard to the research question about whether social support retains a significant association with psychological distress even after all relevant variables are checked.

The sociodemographic variables (sex, age, marital status) and disease duration were entered in the first step. None of these variables showed a significant association with psychological distress. ESR was entered to control for disease activity. Functional status was entered in the third step and proved to be a significant predictor of psychological distress

($\beta = 0.36$, $p \leq 0.001$). The RAI and pain were entered in the next step and RAI did not show a significant association, whereas pain served as a strong and significant predictor ($\beta = -0.40$, $p \leq 0.001$). Furthermore, functional disability ceased to be significant after entering pain into the model. Both social support measures were entered in the fifth step. ESS served as a significant predictor ($\beta = -0.26$, $p \leq 0.01$), but INS was not significant. Initial psychological distress (i.e. psychological distress at T1) was entered in the final step to control for the psychological distress already present at the beginning of the study and served as a highly significant predictor of psychological distress at T4 ($\beta = 0.42$, $p \leq 0.001$). Pain lost its significance, and only ESS remained significant even after entering psychological distress from T1 in the last step ($\beta = 0.21$, $p \leq 0.05$). The whole model accounted for approximately one third of the total variance ($R^2 = 34\%$) in psychological distress at T4, with initial distress explaining a substantial part ($R^2 = 14\%$) (Table IV).

Furthermore, to improve this model, a stepwise regression model was prepared in which variables not showing a significant contribution to the model in the previous analysis were removed. This model is displayed in Table V and shows a pattern similar to that in the previous model with comparable amount of explained variance ($R^2 = 36\%$).

Discussion

The first aim of our study was to investigate the course of psychological distress in early RA patients as well as to explore its associations with joint tenderness, pain and functional disability over time using a longitudinal design. Our second objective was to focus specifically on the associations between social support and psychological distress.

The course of psychological distress in the population under study was observed to be fairly stable, and no significant differences were found at the group level among the four consecutive measurements. Other studies investigating

Table III. Correlations between psychological distress at T4 and independent variables in people with rheumatoid arthritis (Spearman's ρ).

	GHQ (distress) T4
Sex	0.03
Age	-0.02
Marital status (married)	-0.10
Disease duration	-0.09
ESR	-0.05
HAQ	0.28*
RAI	0.25*
NHP (pain)	-0.43**
ESS	-0.33**
INS	-0.24**
GHQ (distress) T1	0.52**

ESR, erythrocyte sedimentation rate; ESS, emotional support satisfaction; GHQ, General Health Questionnaire; HAQ, Health Assessment Questionnaire; INS, Instrumental Support Satisfaction; NHP, Nottingham Health Profile; RAI, Ritchie Articular Index.

* $p < 0.05$; ** $p < 0.01$.

Table IV. Hierarchical regression of explored variables on psychological distress at T4 in people with rheumatoid arthritis.

Predictors	Step1 β	Step2 β	Step3 β	Step4 β	Step5 β	Step6 β
1 Sex (female)	0.08	0.08	-0.04	0.01	0.00	0.05
Age	-0.04	-0.04	-0.11	-0.12	-0.08	-0.01
Marital status (married)	-0.08	-0.08	-0.06	-0.03	-0.02	-0.08
Disease duration	-0.05	-0.05	-0.16	-0.11	-0.10	-0.04
2 ESR		-0.03	-0.10	-0.12	-0.05	0.04
3 HAQ			0.36***	0.04	0.01	0.01
4 RAI				0.00	0.02	0.04
NHP (pain)				-0.40***	-0.32**	-0.22
5 ESS					-0.26*	-0.21*
INS					-0.02	0.03
6 GHQ (distress)T1						0.42***
R ² change (%)	1.6	0.1	9.5	8.1	6.6	14
Adjusted R ² (%)	0	0	6.4	13.4	19.4	33.7
Total R ² (%)		0	11.3	19.4	26	40
F	0.457	0.386	2.308	3.224	3.690	6.304
Df1, Df2	4111	5110	6109	8107	10 105	11 104

ESR, erythrocyte sedimentation rate; ESS, emotional support satisfaction; GHQ, General Health Questionnaire; HAQ, Health Assessment Questionnaire; INS, Instrumental Support Satisfaction; NHP, Nottingham Health Profile; RAI, Ritchie Articular Index.

* $p < 0.05$; ** $p < 0.01$; *** $p < 0.001$.

Table V. Hierarchical regression of explored variables on psychological distress at T4 in people with rheumatoid arthritis (method stepwise, insignificant variables removed).

Predictors	Step1 β	Step2 β	Step3 β	Step4 β
1. HAQ	0.256**	0.022	0.077	0.050
2. NHP (pain)		-0.427**	-0.344**	-0.213*
3. ESS			-0.280**	-0.199*
4. GHQ (distress)T1				0.406**
R ² change (%)	6.6	10.5	7.4	14.2
Adjusted R ² (%)	5.8	15.6	22.4	35.6
Total R ² (%)		17.1	24.5	38.7
F	8.025	11.642	12.084	17.494
Df1, Df2	1,115	2,114	3,113	4,111

ESS, emotional support satisfaction; GHQ, General Health Questionnaire; HAQ, Health Assessment Questionnaire; NHP, Nottingham Health Profile;

* $p < 0.05$; ** $p < 0.01$.

psychological distress in RA patients have shown similar results [6,14]. Results at the individual level are more difficult to interpret however, although a slightly increasing tendency of correlation can be identified. Moreover, the correlations among joint tenderness, pain, functional disability and psychological distress demonstrated an increasing tendency, which shows that these variables may become more closely associated with a patient's psychological functioning as the disease progresses.

In further analysis, the focus was primarily on the previously mentioned associations and regression models were built. The analysis mainly showed that psychological distress experienced at the beginning of the study was the strongest predictor of psychological distress 4 years later. Patients who had elevated levels of distress at the onset of RA, or even before, were found to be at greater risk for higher psychological distress later [6]. When exploring time-lagged associations, initial psychological distress, pain and ESS remained significant in the final model, whereas gender and marital status were not significant. Although gender and age differences are well recognized regarding both psychological distress and social support in the general population, the studied sample consisted solely of early RA patients, which might have affected this finding. Similar results have been reported in other studies focusing on early RA populations [8,14].

Both kinds of social support used in our analysis are considered to be highly relevant in RA as a practical aid and for emotional sustenance [49]. However, it is emotional support that seems to be directly associated with psychological distress, and the analysis shows that it remained significant even after controlling for initial psychological distress. In support of previous studies, it was found that emotional support from the social environment may serve as a protection against psychological distress, although it must be said that these two variables are always interrelated [6,50]. However, instrumental support was not found to be associated with psychological distress in our sample after controlling for the relevant variables. This may be due to the fact that patients adapted well to their condition over the years, and it is psychological vulnerability that is more closely related to their social environment.

Neither joint tenderness, measured using the RAI, nor disease activity, measured using ESR during the first hour, were significantly associated with psychological distress in the regression model. Only pain, measured using the NHP, which is a self-report questionnaire containing items concerned with the subjective feeling of pain while in a certain posture or while performing simple activities (e.g. standing for a while, turning on bed), was found to be significant. These results suggest that subjective measures demonstrate stronger association with psychological distress than laboratory findings or tender joints count. This is consistent with the findings of other studies [6,51].

Despite using a longitudinal design, there are limitations to the study. Not all the patients participated throughout all four waves, and eight patients were not included in the analysis due to their failure to participate in the third wave. This reduced the response rate to 72.5%. The choice of non-parametric tests and their impact on a possible generalization of the findings must also be acknowledged. It should also be mentioned that gender differences and the nature of marital relationships, which were not very strongly controlled in this study, have been shown to have considerable impact on the benefits of social support [34,52,53]. In addition, the sample was predominantly female, which creates certain limitations for a generalization of the findings. Furthermore, Disease Activity Score, a frequently used standard measure, could not be calculated due to missing information about the number of swollen joints, and thus disease activity was monitored by ESR and the tender-joint count. Concerning the measurement of pain and disability, it must be mentioned that both measures are self-reported and high inter-correlations may be partly caused by the similar wording of the items.

To conclude, the findings of the present study suggest that psychological distress showed the highest correlation with initial psychological distress. Pain and emotional support also demonstrated significant correlations with psychological distress in early RA and could serve as an indicator of patient's vulnerability to psychological distress [45].

It could be beneficial to take the social factors addressed in this study into consideration with regard to treatment of people with RA. Early treatment of psychological distress, for example, via participation in support groups and other social activities may prevent an increase in feelings of depression and anxiety. Furthermore, such psychosocial preventive treatment can be a substantial source of emotional support that can enhance the overall quality of life of people with RA.

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