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Patients and spouses coping with inflammatory arthritis: impact of communication and
spousal perceived social support and burden

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Objectives

To guide Therapeutic Patient Education (TPE) programs to improve patients' and spouses' perceived health, we aimed to analyze the effect of the spouse health state and patient–spouse relationship on functional impairment, mental health and self-efficacy of patients with RA or SpA.

Methods

In this observational cross-sectional study, inclusion criteria were age ≥ 18 years and diagnosis of RA or SpA. The outcome criteria were functional impairment and mental health measured by the Medical Outcomes Study Short-Form 12-item version (SF-12-MCS); mental health measured by the General Health Questionnaire (GHQ-12); and self-efficacy by the General Self-Efficacy Scale (GSE Scale). Caregiver–patient relationship was assessed by the Personal Assessment of Intimacy in Relationships (PAIR) questionnaire and the Dyadic Adjustment Scale (DAS); social support by the Social Support Questionnaire-6 and spousal burden by the Zarit questionnaire.

Results

A total of 88 patient–spouse couples were included. Patients were mostly female (N=68, 77%), with mean age 59 (SD 12.6) years; 69% had RA. On bivariate analyses, only spousal burden was associated with patients' functional impairment. Patients' mental health was associated with satisfaction with social support and the dyad relationship. Self-efficacy of patients was associated with spousal burden, satisfaction with social support, spousal anxiety/depression and the dyad relationship. On multivariate analysis, improved mental health and perceived self-efficacy of patients were associated with spousal satisfaction with social support (Beta=0.8, $p=0.1$ with GHQ-12) good communication in the couple (Beta=0.5, $p=0.04$ with SF-12-MCS and Beta=0.4, $p=0.04$ with GSE Scale) and low spousal-assessed burden (Beta=-0.2, $p=0.003$ with GSE Scale).

Conclusion

This study has identified potential focus for intervention. It has highlighted the importance of recognizing the role of couple communication (experiencing an open and fluent exchange of ideas) in the patient's mental health and self-efficacy but also perceived satisfaction with social support of both members of the couple on the patient's mental health.

Keywords: inflammatory arthritis, spouse, relatives, social support, communication

1. Introduction

With inflammatory arthritis (IA), help in physical tasks, emotional and social support is crucial [1,2], and adjustment to the disease necessarily [3] implies adjustment for those who live close to the patient [4]. In addition to the physical or psychological impact of the disease, patients with IA also must reformulate their social trajectory, which includes family and professional and social spaces. The spouse, sometimes despite himself/herself, then plays a strong social support role, which allows the patient to maintain social stability despite the illness. Coping with the disease is then considered an interdependent couple-level process in which cognitive appraisals, stress, emotions, and coping behaviors are shared between spouses [5]. Moreover, symptoms of IA, especially pain or fatigue [6], are mostly invisible and are unpredictable, which has specific consequences, especially on relationships with others [7].

Thus, recommendations specify that therapeutic patient education (TPE), which is part of the care pathway, can be offered to patients' spouses if they wish and if the patient wishes to include the spouses in their care [8,9]. Indeed, the family member may have needs in order to fulfill his or her role as a caregiver. As in couple therapy, improving communication, problem-solving skills and dyadic coping skills can be targets to work on [5].

In rheumatology, the participation of spouses in TPE interventions is often limited to their participation in a few sessions with the patient, but their participation in dedicated sessions [10] or their active involvement in interventions [11] is rare. In rheumatoid arthritis (RA), targeting spouses in TPE is infrequent and had controversial results [12,13]. EULAR recommendations for patient education for people with IA [14] points to the need “to develop and evaluate TPE for significant others (spouses, spouses, family and carers)”.

Studies [15,16] have explored the impact of the characteristics of the caregiver or the relationship within the couple on the patient's health state separately but not simultaneously.

Moreover, studies focused on RA, not spondyloarthritis (SpA) or psoriatic arthritis (PsA). These studies included a small number of patients and were performed before the extensive and early use of biological treatments, which has deeply changed patients' perceived health.

This study, with insight into the effect of the spouse on the patients' perceived health status, should allow us to guide TPE programs to improve patients' and spouses' perceived health. The effect of the family member must be better taken into account to improve TPE programs, which, if such programs are to be individualized, must address these issues. Finally, to interpret the results of TPE intervention studies, the spouse and patient–spouse interaction must be taken into account.

The aim of the study was to analyze the impact of the spouse's health state and the patient–spouse relationship on functional impairment, mental health and self-efficacy of the patient with IA.

2. Methods

2.1. Study design

Data were obtained from a descriptive observational cross-sectional nationwide survey in France between January 2017 and September 2018. Patients were informed of the study objectives and that data collection and analysis were anonymous. All patients completed a paper or online case report form (CRF) and asked their spouse to complete their own CRF. Questionnaires were completed at home.

All applicable regulations were respected, and the project was conducted in accordance with ethical standards in France (authorization from the ethical committee of Nancy university hospital).

2.2. Study population and recruitment

Patients included had a diagnosis of RA, SpA or PsA according to American College of Rheumatology/European League Against Rheumatism (ACR/EULAR), Assessment of SpondyloArthritis international Society (ASAS) or Classification Criteria for Psoriatic Arthritis (CASPAR) criteria, respectively. They were ≥ 18 years old and had a spouse who agreed to participate. Patients with a major comorbidity that may interfere too greatly with the consequences of their main disease were not included. Participants were recruited on a voluntary basis by rheumatologists during their consultations in seven rheumatology departments or by a patient association. They were asked to solicit their spouse to participate.

2.3. Outcome criteria

Quality of life was measured by the Medical Outcomes Study Short-Form 12-item version (SF-12), mental health by the General Health Questionnaire 12 (GHQ-12) and self-efficacy by the General Self-Efficacy Scale (GSE Scale)[17].

The SF-12 physical component summary (PCS) and mental component summary (MCS) scores range from 0 to 100, with higher scores indicating better health-related quality of life (HRQoL). The mean of the scores are 50 (SD 10) in the general population [18].

The GHQ-12 is a short form of the GHQ-60, a self-reporting questionnaire designed to detect individuals who are symptomatic or at risk of developing the common, non-psychotic mental health problems associated with depression, anxiety, somatic symptoms, and social dysfunction [19], with scores ranging from 0 (most distressed) to 100 (least distressed). The questionnaire produces 3 scores reflecting the mental health condition of the respondent: anxiety and depression, social dysfunction and loss of confidence [20].

The GSE Scale is a 10-item scale designed to assess optimistic self-beliefs to cope with various difficult demands in life. Scores range from 10 (worst) to 40 (best) [21].

2.4. Independent variables of interest

The spouse–patient relationship was assessed by the Personal Assessment of Intimacy in Relationships (PAIR) questionnaire and the Dyadic Adjustment Scale (DAS) completed by the patient. The PAIR questionnaire involves 3 dimensions: communication (0-20) (experiencing an open and fluent exchange of ideas), engagement (0-40) (feeling connected with one’s spouse) and shared friends (0-12)(sharing common activities with friends)[22,23].

The DAS [24] involves 2 dimensions: degree of agreement (0-50) and quality of the interactions (0-30). High scores indicate greater agreement with the concept of the dimension.

Social support was assessed by the Social Support Questionnaire (SSQ6), which comprises 2 scores, availability (0-54) and satisfaction (0-36)[25].

Spouses also completed the DAS and the SSQ6 and assessed perceived burden by the Zarit Burden Interview questionnaire. The Zarit Burden Interview assesses the degree to which a caregiver perceives that their caregiving responsibilities have a negative effect on their health, personal and social life, finances and emotional well-being. The score ranges from 0 to 88 (greater burden) [26].

Spouses also completed surveys on comorbidities (Groll functional comorbidity index [27]), mental health (GHQ-12), quality of life (SF-12: PCS and MCS) and self-efficacy (GSE Scale). All questionnaires have been validated in French.

2.5. Study covariates

Several covariates and potential confounders were included in the analyses. Both patients and spouses provided data on sociodemographic characteristics: age, sex, education level

(primary, secondary school or university), occupation (employed or not), size of residence (≤ 2000 , 2,000-200,000 or $\geq 200,000$ people) and length of relationship (years).

Patients reported clinical data (diagnosis: RA, SpA, PsA), disease duration, participation in a therapeutic patient education program and self-reported measures assessing disease activity (Routine Assessment of Patient Index Data 3 [RAPID3] for patients with RA and PsA, Bath Ankylosing Spondylitis Disease Activity Index [BASDAI] for SpA and PsA, and comorbidities (Groll functional comorbidity index, a self-reporting list of 18 diseases associated with the physical dimension of HRQoL). RAPID3 is a composite index of 3 patient self-reporting measures (0-30): physical function, pain, and patient global assessment. The BASDAI measures patient-reported disease activity (0, no activity, to 10, high level of activity) in patients with SpA. One open-ended question on the reaction of patients and spouses ended the questionnaire: “How did your close one react to your illness?” and “How did you deal with your close one's illness?”

2.6. Analyses

The scores for the questionnaires were calculated according to published recommendations. The data are described with number and percentage for qualitative variables and mean and standard deviation (SD) for quantitative variables (or median and range for non-normally distributed data). Patient–spouse agreement on common data (SSQ6 and DAS) was analyzed with Spearman correlation coefficients.

Data analysis involved multivariable regression models for each dimension of the outcome criteria (SF-12 PCS and MCS composite scores, GHQ-12 and GSE Scale). Candidate variables with $p < 0.1$ on bivariate analysis (ANOVA with one factor with variance equality; Kruskal-Wallis test otherwise for qualitative variables; test from a simple linear regression for quantitative variables) were retained in multivariable models at $\alpha=0.05$. A stepwise

selection was used to keep the most relevant variables in the model. The R-squared value, the percentage of the variation in the response variable explained by a linear model, was computed. Statistical analyses involved using SAS v9.4. $P < 0.05$ was considered statistically significant.

Themes of the open-ended question linked to the themes measured by the self-reported questionnaires were extracted.

3. Results

A total of 88 patient–spouse couples were included. Patients were mostly female ($N=68$, 77%), with mean age 59 (SD 12.6) years; 69% had RA, mean disease duration was 16 years (range 1-63) (Table 1). The mean age of spouses was 60 (SD 13.5) years, and 35 (45%) were still working. Patients showed low PCS and MCS scores, but scores for spouses did not differ from those for the general population (mean score 50).

The agreement between patients and spouses in assessing social support and the spouse–patient relationship was low for the SSQ6 satisfaction score ($R = 0.17$) and moderate for the other scores: SSQ6 availability score ($R = 0.31$), DAS degree of agreement score ($R = 0.43$), DAS quality of interactions score ($R = 0.48$), and total DAS score ($R = 0.50$).

On bivariate analysis (Table 2), functional impairment of patients was associated with spousal burden and type of IA and comorbidities. Mental health was associated with patients and spouses' social support (satisfaction scores), couple relationship (PAIR communication and engagement scores, DAS degree of agreement and quality of the interaction assessed by patients), and age, sex, and IA. Self-efficacy was associated with spousal burden, social support (satisfaction scores), spousal anxiety and depression, couple relationship (PAIR communication score and DAS degree of agreement assessed by patients) and patient

comorbidities. The availability of social support and the dimension “shared friends” on the PAIR questionnaire were not associated with the different outcome criteria.

On multivariate analysis (Table 3), patients’ mental health and perceived self-efficacy were improved with good communication in the couple, spouses’ satisfaction with social support and low spousal burden.

A total of 61 couples answered the open questions “How did your spouse react to your illness?” for the patient, and “How did you deal with your spouse’s illness?” for the spouse. Several answers were linked to the themes of communication or social support (Table 4). Couples described their communication as important and long or virtually absent. Long discussions allowed both the patient and spouse to better cope with the disease together. Listening was highlighted. In contrast, other couples addressed the lack of communication, shown by lack of understanding, fear or wish to protect oneself or because the patient wants to protect her/his spouse. One spouse (man) expressed the idea that “we’re never the other” and that a disease cannot be fully understood when not experienced, which does not prevent communication.

“I considered that my sick wife was living a form of non-communicable experience, to which I intrinsically stayed outside. At the same time, I am part of the solution, and I must intervene only when asked and continue to live my life”.

Support came from spouses but sometimes from beyond, for example, from healthcare providers (3 couples) or from patient associations (1 couple).

4. Discussion

Our study identified potential focus for intervention. It has highlighted the importance of recognizing the role of couple communication (experiencing an open and fluent exchange of ideas) on the mental health and self-efficacy of the patient with IA but also that of

perceived satisfaction with social support of both members of the couple (not just the patient) on the patient's mental health. Finally, the perceived spousal burden was associated with the patient's self-efficacy. In contrast, the other dimensions of the patient-spouse relationship were not independently associated with HRQoL and none of the spouse variables or the spouse-patient relationship affected the PCS score of HRQoL.

The association of the patient's mental health with the spouse's assessment of satisfaction with social support is a new insight into study of the impact of environmental factors on patient perceived health. It highlights the importance of the quality of perceived social support beyond the close one or family support. Social isolation is an important concern of patients with IA. In a previous study, patients described their life as "*a restricted life*" and mentioned different reasons. Going out or entertaining at home is difficult because of the symptoms, especially fatigue or pain. Invisibility of the disease can create misunderstandings, and close friends do not really understand the couple difficulties. Finally, after cancelling several invitations, they are no longer invited [21]. Spouses also report that they had given up shared recreational activities and had difficulty making future plans [4].

In multivariate analysis, among spouse health state and patient-spouse relationship dimensions, communication (experiencing an open and fluent exchange of ideas) is more important than other dimensions, engagement (feeling connected with one's spouse), shared friends (sharing common activities with friends), degree of agreement and quality of the interactions. Communication was associated with congruence in couples, which in turn affected the couple's quality of life. Indeed, a similar appraisal of the disease and situation by both the patient and spouse allow them to cope together, make decisions together, and allow for a better dyadic adjustment [28,29]. The importance of patient verbal disclosure has also been highlighted : with verbal expression, pain is probably better understood than nonverbal expression of pain and increases interactions and trust [30]. The impact of listening behaviors

was also mentioned in the free comments of our study and in the literature. “Poor” listeners engaged much more in giving advice or offering support that was negative or counterproductive [31]. Finally, a few patients explained in the free comments that they do not communicate because of lack of understanding, fear or wish to protect oneself or because the patient wants to protect her/his spouse.

Spousal burden was inversely correlated with patient self-efficacy on multivariable analysis and inversely correlated with patient mental and physical functioning on bivariate analysis. This finding probably reflects the severity of the disease, but the burden for the close one does not depend solely on the patient’s health state. Indeed, spousal physical health, self-efficacy expectation with respect to helping with household activities and the number of children explain a large part of the spousal burden [32].

We acknowledge some limitations in our study. First, because the mean level of marital satisfaction was in the average range, whether the results can be generalized to distressed couples is unknown. The mean age of the sample was also rather high, and most couples were in long-term marriages. The instruments used to measure the spouse–patient relationship were developed for the general population and not to assess the spouse–patient relationship of couples facing a chronic disease. As in all cross-sectional studies, we did not explore causal relationships but rather associations. Finally, we did not have enough power to analyze whether the associations between the spouse’s health state and patient–spouse relationship and functional impairment, mental health and self-efficacy differed between RA and SpA patients.

However, the study has some strengths. The number of couples was high for a study involving couples difficult to recruit. Several dimensions of couple interactions and environment were not previously explored, and the designs of this study and the whole project of development of a TPE for significant others used mixed methods [33,34]. Indeed, guide the

development of such a program, a needs assessment is necessary. This assessment combines at best a qualitative approach with interviews with couples [21,35] and a quantitative approach to determine which spouse health state and patient–spouse relationship characteristics are associated with better patient health. A survey allows for collecting data among a larger sample than with qualitative interviews, to recruit a sample a little less selected and to further explore some themes addressed by couples during the interviews such as communication and social impact of the disease.

Implications for interventions

The effect of the family member must be better taken into account to improve therapeutic patient education programs, which, if they are to be individualized, must address these issues. This study, with insights into the effect of the spouse on the patient’s perceived health status, allowed us to guide TPE programs aiming to improve patients' and spouses’ perceived health and include modules for patients with their spouse or spouses only if necessary. Interventions to prevent marital distress exist and can be used to support the development of interventions for couples, one of whom has a chronic disease.

Our study identified the communication between the patient and spouse as a potential focus for intervention. Actually, communication has become a standard target in couple therapy and relationship enhancement programs [5]. In the program Couples Coping Enhancement Training, spouses first learn to improve their ability to communicate their stress explicitly to their spouse, including discriminating facts from emotions. This step is then followed by training the spouse on how to respond to their spouse's stress with dyadic coping efforts that meet their spouse's needs [36]. One of the objectives of this program was to increase the mutual understanding of each other's functioning, thereby leading to mutual empathy, sharing of emotions and trust.

The role of patient perceived social support on patient perceived health has long been recognized, but spousal perceived social support is also important. Interventions aimed at helping patients and families deal with problematic aspects of social support may help enhance the well-being of individuals and families living with RA [37].

Development of support strategies to prevent or decrease high levels of negative caregiver burden and increase the focus of the spouse on the positive aspects of caregiving could improve patient outcomes [38]. Support strategies could focus on reducing the burden caused by a disrupted schedule, for example, and take into consideration spousal physical health (physical and mental) and self-efficacy expectation with respect to helping with household activities [38]. Help in seeking support from other family members or beyond the family could also be a way to help the spouse.

Further studies are needed to reach and better understand couples with problematic functioning, develop and evaluate interventions for couples affected by chronic diseases and create motivation sources to reach both patients and spouses [39]. Interdisciplinarity in research and patient support is a key element in improving patient and couple care, and it is very important to look to other disciplines (e.g, here, couple therapy) and use their expertise.

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References

- [1] Lehman AJ, Pratt DD, DeLongis A, Collins JB, Shojania K, Koehler B, et al. Do spouses know how much fatigue, pain, and physical limitation their partners with rheumatoid arthritis experience? Implications for social support: Spousal Concordance on Fatigue, Pain, and Physical Limitation in RA. *Arthritis Care Res* 2011;63:120–7.
- [2] Sterba KR, DeVellis RF, Lewis MA, DeVellis BM, Jordan JM, Baucom DH. Effect of couple illness perception congruence on psychological adjustment in women with rheumatoid arthritis. *Health Psychol* 2008;27:221–9.
- [3] Abraído-Lanza AF, Revenson TA. Illness intrusion and psychological adjustment to rheumatic diseases: A social identity framework. *Arthritis Rheum* 2006;55:224–32.
- [4] Matheson L, Harcourt D, Hewlett S. ‘Your whole life, your whole world, it changes’: partners’ experiences of living with rheumatoid arthritis. *Musculoskeletal Care* 2010;8:46–54.
- [5] Falconier MK, Jackson JB, Hilpert P, Bodenmann G. Dyadic coping and relationship satisfaction: A meta-analysis. *Clin Psychol Rev* 2015;42:28–46.
- [6] Toye F, Seers K, Barker KL. Living life precariously with rheumatoid arthritis - a mega-ethnography of nine qualitative evidence syntheses. *BMC Rheumatol* 2019;3. <https://doi.org/10.1186/s41927-018-0049-0>.
- [7] Paul-Savoie E, Bourgault P, Potvin S, Gosselin E, Lafrenaye S. The Impact of Pain Invisibility on Patient-Centered Care and Empathetic Attitude in Chronic Pain Management. *Pain Res Manag* 2018;2018:1–8.
- [8] HAS_etp_-_comment_elaborer_un_programme_-_recommandations_juin_2007.pdf n.d.
- [9] Daien C, Hua C, Gaujoux-Viala C, Cantagrel A, Dubremetz M, Dougados M, et al. Update of French society for rheumatology recommendations for managing rheumatoid arthritis. *Joint Bone Spine* 2019;86:135–50.
- [10] Van Abbema R, Van Wilgen CP, Van Der Schans CP, Van Ittersum MW. Patients with more severe symptoms benefit the most from an intensive multimodal programme in patients with fibromyalgia. *Disabil Rehabil* 2011;33:743–50.
- [11] Bernardy K, Klose P, Busch AJ, Choy EHS, Haeuser W. Cognitive behavioural therapies for fibromyalgia. *Cochrane Database Syst Rev* 2013. <https://doi.org/10.1002/14651858.CD009796.pub2>.
- [12] Riemsma RP, Taal E, Rasker JJ. Group education for patients with rheumatoid arthritis and their partners. *Arthritis Rheum* 2003;49:556–66.
- [13] van Lankveld W, van Helmond T, Näring G, de Rooij DJ, van den Hoogen F. Partner participation in cognitive-behavioral self-management group treatment for patients with rheumatoid arthritis. *J Rheumatol* 2004;31:1738–45.
- [14] Zangi HA, Ndosu M, Adams J, Andersen L, Bode C, Boström C, et al. EULAR recommendations for patient education for people with inflammatory arthritis. *Ann Rheum Dis* 2015;74:954–62.
- [15] Stephenson E, DeLongis A, Esdaile JM, Lehman AJ. Depressive Symptoms and Rheumatoid Arthritis: Spouse Empathic Responding as a Buffer: Spouse Depression and Empathic Responding in RA. *Arthritis Care Res* 2014;66:532–41.

- [16] Martire LM, Stephens MAP, Schulz R. Independence centrality as a moderator of the effects of spousal support on patient well-being and physical functioning. *Health Psychol* 2011;30:651–5.
- [17] Schwarzer R, Jerusalem M. Generalized Self-Efficacy Scale. In: In, Weinman J, Wright S, and Johnson M, editors. *Meas. Health Psychol. Users Portf. Causal Control Beliefs*; Windsor England: NFER-NELSON; 1995, p. 35–7.
- [18] Gandek B, Ware JE, Aaronson NK, Apolone G, Bjorner JB, Brazier JE, et al. Cross-validation of item selection and scoring for the SF-12 Health Survey in nine countries: results from the IQOLA Project. *International Quality of Life Assessment. J Clin Epidemiol* 1998;51:1171–8.
- [19] Goldberg DP, Gater R, Sartorius N, Ustun TB, Piccinelli M, Gureje O, et al. The validity of two versions of the GHQ in the WHO study of mental illness in general health care. *Psychol Med* 1997;27:191–7.
- [20] Salama-Younes M, Montazeri A, Ismaïl A, Roncin C. Factor structure and internal consistency of the 12-item General Health Questionnaire (GHQ-12) and the Subjective Vitality Scale (VS), and the relationship between them: a study from France. *Health Qual Life Outcomes* 2009;7:22.
- [21] Brignon M, Vioulac C, Boujut E, Delannoy C, Beauvais C, Kivits J, et al. Patients and relatives coping with inflammatory arthritis: Care teamwork. *Health Expect Int J Public Particip Health Care Health Policy* 2020;23:137–47.
- [22] Constant E, Vallet F, Nandrino J-L, Christophe V. Personal assessment of intimacy in relationships: Validity and measurement invariance across gender. *Rev Eur Psychol Appliquée European Rev Appl Psychol* 2016;66:109–16.
- [23] Schaefer MT, Olson DH. Assessing Intimacy: The Pair Inventory*. *J Marital Fam Ther* 1981;7:47–60.
- [24] Antoine P, Christophe V, Nandrino J-L. Échelle d'ajustement dyadique : intérêts cliniques d'une révision et validation d'une version abrégée. *L'Encéphale* 2008;34:38–46.
- [25] Bruchon-Schweitzer M, Rasclé N, Gélié F, Fortier C, Sifakis Y, Constant A. Le questionnaire de soutien social de Sarason (SSQ6): Une adaptation française. [The Sarason's Social Support Questionnaire (SSQ6): A French adaptation.]. *Psychol Fr* 2003;48:41–53.
- [26] Zarit SH, Reever KE, Bach-Peterson J. Relatives of the impaired elderly: correlates of feelings of burden. *The Gerontologist* 1980;20:649–55.
- [27] Groll DL, To T, Bombardier C, Wright JG. The development of a comorbidity index with physical function as the outcome. *J Clin Epidemiol* 2005;58:595–602.
- [28] Creameans-Smith JK, Stephens MAP, Franks MM, Martire LM, Druley JA, Wojno WC. Spouses' and physicians' perceptions of pain severity in older women with osteoarthritis: dyadic agreement and patients' well-being: *Pain* 2003;106:27–34.
- [29] Lyons KS, Jones KD, Bennett RM, Hiatt SO, Sayer AG. Couple perceptions of fibromyalgia symptoms: The role of communication: *Pain* 2013;154:2417–26.
- [30] Wilson SJ, Martire LM, Keefe FJ, Mogle JA, Stephens MAP, Schulz R. Daily verbal and nonverbal expression of osteoarthritis pain and spouse responses: *Pain* 2013;154:2045–53.
- [31] Kuhn R, Bradbury TN, Nussbeck FW, Bodenmann G. The power of listening: Lending an ear to the partner during dyadic coping conversations. *J Fam Psychol* 2018;32:762–72.

- [32] Riemsma RP, Taal E, Rasker JJ, Klein G, Bruyn GAW, Wouters JMGW, et al. The burden of care for informal caregivers of patients with rheumatoid arthritis. *Psychol Health* 1999;14:773–94.
- [33] Johnson RB, Onwuegbuzie AJ, Turner LA. Toward a Definition of Mixed Methods Research. *J Mix Methods Res* 2007;1:112–33.
- [34] Leech NL, Onwuegbuzie AJ. A typology of mixed methods research designs. *Qual Quant* 2009;43:265–75.
- [35] Untas A, Vioulac C, Boujut E, Delannoy C, Poivret D, Rat A-C, et al. What Is Relatives' Role in Arthritis Management? A Qualitative Study of the Perceptions of Patient-Relative Dyads. *Patient Prefer Adherence* 2020;14:45–53.
- [36] Bodenmann G, Pihet S, Kayser K. The relationship between dyadic coping and marital quality: A 2-year longitudinal study. *J Fam Psychol* 2006;20:485–93.
- [37] Coty M-B, Wallston KA. Problematic Social Support, Family Functioning, and Subjective Well-Being in Women with Rheumatoid Arthritis. *Women Health* 2010;50:53–70.
- [38] Jacobi CE, van den Berg B, Boshuizen HC, Rupp I, Dinant HJ, van den Bos GA. Dimension-specific burden of caregiving among partners of rheumatoid arthritis patients. *Rheumatology(Oxford)* 2003;42:1226–33.
- [39] Beauvais C. Motivational interviewing to improve treatment adherence. *Joint Bone Spine* 2019;86:535–7.

Table 1: Patients' and spouses' characteristics (n=88 couples)

		Patients		Spouses	
		Mean	(SD)	Mean	(SD)
Age (years)		59.0	(12.6)	60	(13.5)
Sex, N (%)	Women	68	(77.3)	24	(27.3)
Length of relationship (years)		28.2	(16.5)		
Education level, (N (%))	Primary school	10	(11.4)	7	(8.0)
	Secondary school	44	(50.0)	48	(55.2)
	University	34	(38.6)	32	(36.8)
Occupation, N (%)	Employed	34	(45.3)	35	(44.9)
Retired, N (%)		37	(48.7)	48	(62.3)
Size of residence (no. inhabitants), N (%)	≥ 200,000	11	(12.9)		
	2,000 to 200,000	31	(36.5)		
	≤2,000	41	(48.2)		
Inflammatory arthritis, N (%)	Rheumatoid arthritis	60	(69.0)		
	Spondyloarthritis or psoriatic arthritis	27	(31.0)		
Disease duration (years)		16.1	(13.4)		
RAPID3	[0-30]	10.4	(6.5)		
BASDAI	[0-10]	5.7	(1.8)		
Participation in a TPE program, N (%)	Yes	30	(34.5)	9	(11)
Comorbidity (Groll index)	[0-18]	1.6	(1.7)	1.1	(1.3)

SF-12	PCS [0-100]	37.7	(11.4)	50.8	(8.3)
	MCS [0-100]	46.5	(8.3)	49.1	(6.6)
GHQ-12	Anxiety, depression [0-100]	54.6	(17.8)	65.2	(9.3)
	Social dysfunction [0-100]	57.7	(23.3)	72.2	(15.9)
	Loss of confidence [0-100]	73.9	(27.8)	83.1	(20.3)
GSE Scale	[10-40]	27.8	(6.1)	31.3	(4.7)
SSQ6	Availability [0-54]	13.7	(8.2)	12.4	(10.0)
	Satisfaction [0-36]	28	(7.5)	27.1	(8.7)
DAS	Degree of agreement [0-50]	35	(8.5)	37.2	(7.0)
	Quality of interactions [0-30]	20	(6.0)	19.8	(5.7)
PAIR	Communication [0-20]	14.6	(4.0)		
	Engagement [0-40]	26.8	(10.7)		
	Shared friends [0-12]	8.2	(2.8)		
Zarit [0-88]				18.4	(14.4)

RAPID3, Routine Assessment of Patient Index Data 3; BASDAI, Bath Ankylosing Spondylitis Disease Activity Index; TPE, Therapeutic Patient Education; SF-12: Medical Outcomes Study Short-Form 12-item version; PCS, physical component summary; MCS, mental component summary; GHQ-12, General Health Questionnaire 12; GSE Scale: General Self-Efficacy Scale; PAIR, Personal Assessment of Intimacy in Relationships; SSQ6, Social Support Questionnaire 6; DAS, Dyadic Adjustment Scale

Table 2: Association of spouses' health state and spouse–patient relationship with functional impairment, mental health and self-efficacy of the patient with IA: bivariate analysis

		Patient SF-12 PCS score	Patient SF-12 MCS score	Patient GHQ-12 Mental health	Patient GSE Scale
		r	r	r	r
Spouse					
Comorbidity		0.39	0.63	0.29	-0.54
SF-12	PCS	0.08	0.00	0.11	0.1
	MCS	0.17	0.16	0.72 ^a	0.14
GHQ-12	Anxiety, depression	0.04	0.10	0.67 ^b	0.15 ^a
	Social dysfunction	0.08	0.07	0.38 ^a	0.07
	Loss of confidence	-0.07	0.05	0.14	0.02
GSE Scale		0.10	0.19	-0.27	-0.03
SSQ6	Availability	0.08	-0.11	0.25	0.05
	Satisfaction	0.02	0.28 ^a	1.03 ^c	0.23 ^b
Zarit (spousal burden)		-0.28 ^b	-0.08	-0.52 ^b	-0.22 ^c
Patient					
Length of relationship		0.15	0.05	0.26 ^a	0.01
PAIR	Communication	-0.07	0.76 ^b	1.13 ^a	0.34 ^a
	Engagement	-0.02	0.18 ^a	0.04	0.11
	Shared friends	0.31	0.39	0.15	0.17
DAS	Degree of agreement	0.35	0.28 ^a	0.80 ^b	0.27 ^c
	Quality of interactions	-0.11	0.34 ^a	-0.10	0.1
SSQ6	Availability	-0.18	-0.07	-0.28	-0.14
	Satisfaction	0.09	0.40 ^b	0.90 ^b	0.18 ^a

SF-12: Medical Outcomes Survey Short-Form 12-item version; PCS, physical component summary; MCS, mental component summary; GHQ-12, General Health Questionnaire 12; GSE Scale: General Self-Efficacy Scale; PAIR, Personal Assessment of Intimacy in Relationships; SSQ6, Social Support Questionnaire 6; DAS, Dyadic Adjustment Scale

^ap<0.05, ^bp <0.01, ^cp <0.001

Table 3: Association of spouse's health state and spouse-patient relationship with functional impairment, mental health and self-efficacy of the patient with IA: multivariate analysis

	Patient SF-12 PCS*	Patient SF-12 MCS*	Patient GHQ-12 Mental health*	Patient GSE Scale*
	Beta	Beta	Beta	Beta
Spouse data				
Social support (satisfaction)		0.20 ^a	0.80 ^b	
Burden (Zarit)				-0.2 ^b
Patient data				
Communication (PAIR)		0.50 ^a		0.4 ^a
R ² spouse	0.12	0.17	0.27	0.27
R ² patient	0.19	0.40	0.35	0.29
R ² global	0.19	0.41	0.49	0.30
*adjustment on patients' comorbidity index.				
^a p<0.05,	^b p	<0.01,	^c p	<0.001

Table 4. Perception of the response of the spouse to the patient's disease.

Theme	Verbatim	Participant
Communication		
Important and long (7 couples)	<i>My wife was very scared. We talked for a long time.</i>	Patient man
	<i>She took care of the organization (planning, treatment follow-up, appointments, symptoms etc.). This allowed her to manage better and better</i>	
	<i>When he was diagnosed, I took it very badly. Thanks to our long discussions, I learned to live with my spouse's disease. We support each other; the disease has become a member of the family.</i>	Spouse woman
Listening (3 couples)	<i>He was present, available and listening.</i>	Patient woman
Absence of communication (4 couples)	<i>I have the feeling that he doesn't measure the intensity of my pain; he doesn't talk about it much.</i>	Patient woman
	<i>My husband isn't happy about it. So, he doesn't talk about it, protects himself and doesn't want to hear sometimes the evils that can gnaw at him.</i>	Patient woman
	<i>I find it hard to understand her and know how she feels, and I think I'd rather ignore it for fear it'll get worse.</i>	Spouse man
	<i>He doesn't realize everything because I hide it as much as possible so as not to worry him and ruin his life.</i>	Patient woman

Social support

I was a little worried at first, but I was reassured by the dialogue with my spouse and the meeting with the specialists. Patient man

I ended up accepting it after meetings with practitioners and the Andar Club [Association Nationale de Défense contre l'Arthrite Rhumatoïde, patient association] Patient women
