

What Is Relatives' Role in Arthritis Management? A Qualitative Study of the Perceptions of Patient-Relative Dyads

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Purpose: The main aim of patient education is to maintain or improve quality of life. It is mostly focused on patients even if families might be included. The aim of this study was to explore patients' and relatives' perceptions and experiences about the role of relatives in disease management in chronic inflammatory arthritis in order to provide insight into how patient education programs might include relatives.

Methods: Individual semi-structured interviews were conducted with 20 patients (13 with polyarthritis; 7 with spondyloarthritis) and one of their relatives (N=40). A thematic analysis following an inductive approach was carried out using the QDA-Miner Software (inter-coder agreement 0.7).

Results: The analysis revealed three relevant themes. The first was their perception of relatives' general roles, which included technical skills, knowledge about the disease and interpersonal skills. The other two themes dealt with their specific relationship: the dyad relationship (including the usual relationship and in the context of the disease) and the help relationship (including practical assistance and emotional help).

Conclusion: The results show the wide-ranging role of relatives in practical and emotional support, the complexity of patient-relative interactions regarding requests for help, their relationship and ability to share difficulties. This study gives indications about how to include relatives in TPE programs and emphasizes the importance of developing interventions for patient-relative dyads regarding the practical and emotional management of the disease, as well as interactions concerning help. Those interventions should enhance patients and relatives' quality of life.

Keywords: caregivers, patient education, disease management, chronic arthritis, quality of life, partner

Introduction

Chronic inflammatory arthritis (IA: rheumatoid arthritis, spondyloarthritis) is a progressive and irreversible inflammation of the joints. It induces high levels of pain, disability and intense fatigue. Therapeutic Patient Education (TPE) for people living with such a chronic disease is extremely important as it helps them adapt to and cope with the impact of the disease and treatments. According to the World Health Organization (WHO),¹ TPE:

helps patients acquire or maintain the skills they need to manage their life with a chronic disease in the best possible way. It covers organized activities, including psychosocial support, designed to make patients fully aware about their disease and to inform them

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about care, hospital organization and procedures, and health- and disease-related behaviors. It helps patients and their families understand and deal with the disease and its treatment together, in order to maintain or even improve quality of life.

TPE has shown many important impacts in patients with chronic diseases.² In IA, TPE has shown several benefits, mostly short-term, such as improvements in health-related quality of life, knowledge, coping behavior, pain, disability and depression.³

To deal with illness, patients are often dependent on practical and emotional support and care from relatives, especially partners.⁴ Several studies have explored the effect of relatives on patient adjustment to IA. For example, when couples can share similar feelings, understand each other and mutually adjust, the patients present less anxiety and depression and a higher functioning ability.⁵ However, if relatives criticize the patient or present depressive affects, this has a harmful effect on patient mental health and disease evolution.⁶

Interpersonal problems that can occur with relatives may also be related to the impact of IA upon the relatives' quality of life and psychosocial burden.⁶⁻⁸ Studies have shown that the emotions described by relatives range from anger, guilt, helplessness and resentment, to feelings of loss, worry and fear of the future.⁸⁻¹¹ In rheumatoid arthritis, patient caregivers present a high burden related to ruptures in their time schedule, a lack of family support and financial problems.¹² This feeling of burden increases when the patient is limited in his/her daily activities and when the caregiver has health issues. However, many partners seem to adopt a joint approach to manage the illness, working together as a couple to cope with IA.⁸

TPE programs are largely developed for patients whereas few programs integrate families, even though according to the WHO,¹ TPE is designed to help patients and families. In IA, two studies showed that the participation of the relative in TPE sessions did not significantly improve the patient's overall health.^{4,13} However, in interventions including families, relatives are almost exclusively integrated in order to help the patient manage his/her illness.¹⁴⁻¹⁶ Relatives' own difficulties and patient-relative relationship are not considered.

According to Zandig et al,³ the research agenda in IA points out the need "to develop and evaluate patient education for significant others (partners, spouses, family and carers)". If research highlights the importance of relatives in supporting patients with IA and the impact that the condition can have on them, there is a need for further research in order to understand

better how relatives might be integrated into TPE. The aim of the present study was to explore patients' and relatives' perceptions and experiences about the role of relatives in disease management. Therefore, it focused on patient-relative dyads living with IA. It was anticipated that a better understanding of their general perceptions and specific experience would help in understanding their needs and expectations and consequently provide insight into how TPE might include relatives.

Methods

Sample

Participants were recruited by rheumatologists during their consultations in seven rheumatology departments located in medium or large cities in different regions in France covering urban and rural areas, as well as through a patient association. Inclusion criteria for patients were: having rheumatoid arthritis or spondyloarthritis with medical follow-up; agreeing to take part in the study with a relative; being at least 18 years old; having signed an informed consent. Exclusion criteria were: patients presenting a major comorbidity that might increase the burden of IA (e.g., stroke, cancer, etc.); patients being caregivers themselves.

Inclusion criteria for relatives were: willing to participate and feeling interested in the patient's arthritis; being at least 18 years old; having signed an informed consent.

Relatives were invited to take part in the study by the patients or directly during a consultation when they were present.

Interviews and Study Procedure

After obtaining their informed consent, a psychologist called the participants to schedule an interview. Patients and relatives had to complete a self-reported questionnaire with socio-demographic and medical information (age, gender, education, family and occupational status, type of disease and length since diagnosis) before the interview was undertaken. Face to face interviews were conducted by three psychologists specializing in health psychology. At the end of the interviews, a second self-reported questionnaire were given to each participant. Patients had to complete a measure of disease activity (Routine Assessment of Patient Index Data [RAPID3] for those with rheumatoid arthritis and Bath Ankylosing Spondylitis Disease Activity Index [BASDAI] for those with spondyloarthritis) and a measure of their anxiety and depressive symptoms (Hospital Anxiety and Depression

Scale [HADS]). Relatives were asked to complete the same measure of anxiety and depression as well as a measure of their burden (Zarit burden scale).

Interviews were undertaken in the hospital center in which the patient was followed-up for IA or in their home. Interviews lasted 60 to 90 mins. They were audio-recorded and subsequently transcribed verbatim. The interviews were semi-structured and conducted until data saturation was achieved.

The interview guide was built by the project working group, composed of rheumatologists with experience in TPE, methodologists, psychologists, dieticians and a representative of a patient association. A pilot test was done with 3 dyads. As no problem or difficulty was observed, no change was made in the interview schedule.

The first part of the interview was carried out by two psychologists with the patient-relative dyad. During the second part of the interview, the patient and the relative were interviewed individually by one of the two psychologists. The interview guide is described in [Figure 1](#). The results presented in this paper are drawn from the second part of the interview. The results of the first part have been published in another paper.¹⁷

Please note qualitative studies as this one are not obliged by the French law to be submitted to an ethical committee since it does not aim at introducing medical or therapeutic changes in the patient's care. Therefore, this study was not submitted to an ethical committee when it was conducted. However, the CER-Paris Descartes, as an ethics support service, was questioned to be reassured on the ethical dimension of this research when this paper was submitted. It was confirmed that this protocol was in conformity with the international recommendations on the ethics of research as stipulated by the Helsinki Declaration.

Data Analysis

A thematic analysis was conducted by two psychologists of the group (CD, CV), following a general inductive approach.¹⁸ This type of qualitative analysis enables the researcher to extract themes from the participants' discourse in order to capture their perception of the studied subject. Thus, after reading all the transcripts, the two investigators isolated themes and subthemes and created a coding schedule. After discussion with part of the research team (CD, CV, AU, EB), a coding schedule was built, identical for the analysis of both patient and relative transcripts.

A theme was defined as a topic sufficiently distinctive for the researcher to recognize it and for it to provide important meaning regarding the research question.

A "main theme" appeared in all interviews and "subthemes" appeared in at least 25% of interviews. Nevertheless, a few subthemes appearing in less than 25% of interviews were kept, given the new information they provided.

Transcripts were loaded into the QDA-Miner software, which was used to facilitate the analysis. Both investigators conducted blind coding sessions in order to refine the coding schedule, which was then discussed. To guarantee rigorous data, all steps of the analysis were discussed and validated by the research team. The final analysis resulted in a free marginal score of 0.721, which shows good inter-investigator agreement.

Results

Characteristics of the Population

There were forty participants in the study: twenty patients with one of their relatives. Thirteen patients had rheumatoid arthritis and 7 had spondyloarthritis. Mean duration since diagnosis was 12.8 years. Relatives were mostly partners (90%). The mean age was 59.5 for patients and 60.0 for relatives. Regarding gender, patients were mostly females (14) and relatives men (12). Most of them attended high school or less and were retired. All participant characteristics are presented in [Table 1](#).

Participants' Discourse

The analysis revealed 11 main themes: 1) Perception of relatives' general roles expected regarding the disease; 2) Patients' reactions and difficulties; 3) Relatives' reactions and difficulties; 4) Dyad relationship; 5) Help relationship; 6) Relationships with others (family, friends, etc.); 7) Activities; 8) Disease representation; 9) Healthcare perception; 10) Help that healthcare professionals can provide; 11) Patients' therapeutic education. In this paper, we present and discuss three themes that can be brought into perspective and give a critical insight: Perception of relatives' general roles, Dyad relationship and Help relationship. The other themes are presented in [Appendix 1](#).

Perception of Relatives' General Roles Expected Regarding the Disease

Patients and relatives described what the role of the relative should be. First, they are expected to have some technical skills, although at a minor level. For instance, relatives are expected to know how to help the patient with his/her treatment injections, even to do the injection themselves, and to help reduce the patient's pain and its consequences in general.

Knowing how to do ... shots! (Patient 15)

First part: patient-relative dyad interview

- How would you describe your relationship?
- Do you talk about the illness together?
- What is the impact of the illness on your relationship?
- Which difficulties do you face?
- What help could health professionals provide you with?

Second part: individual patient and relative interviews

The questions presented below are those that patients were asked. The same questions were adapted to relatives in order to have their opinion.

- In your opinion, what is the role or place of relatives regarding the illness?
- What should the relative know about the illness? What should be his/her practical know-how about the illness?
- How does your relative react toward your illness?
- What is your relative's involvement in your illness?
- What help does he/she provide you with?
- How do you feel he/she understands your difficulties and needs?
- What do you expect from him/her?
- What difficulties do you think your relative faces?
- When you do not feel well, do you ask your relative for help? Why (not)?
- Have you previously felt that your relative could not help you? If yes, what did you notice? What did you do?
- Does your relative have projects?
- What help could health professionals provide you with?
- Have you already taken part in a patient education program? If yes, did your relative go with you? What did you gain from it?
- If patient education was designed for relatives, what would your suggestions be?

Figure 1 The interview guide

So I think this is important, that ... relatives, or a child, or a husband, know what to do to ease [the patient's] suffering.
(Relative 17)

have some medical knowledge regarding the disease, its treatments and consequences, and also understand more precisely the painful repercussions.

Relatives should also have knowledge about the disease: they should know "everything", or as much as the patient,

He should know as much as the patient does: what pain does the patient endure? What treatments are given or are

Table 1 Characteristics of Patients and Relatives

	Patients (N = 20)	Relatives (N = 20)
Demographics		
Mean age (SD, interval)	59.5 (15.1; 27–79)	60.6 (13.1; 39–83)
Gender (men vs. women)	6 vs. 14	12 vs. 8
Education		
High school or less	12	13
Attended college	8	7
Family status		
Married/common-law union	19	20
Mean years of couple duration (SD, interval)	27.5 (17.6; 1.5–57)	
Have at least one child	15	17
Relative taking part in the study		
Partner	–	18
Mother	–	1
Friend	–	1
Occupational status		
Employed	3	7
Retired	13	11
Disabled or unemployed	4	2
Medical		
Disease		
Rheumatoid arthritis	13	–
> Disease activity* (mean RAPID3 score, SD, interval)	10.4 (5.8; 5.5–18.3)	–
Spondyloarthritis	7	–
> Disease activity** (mean BASDAI score, SD, interval)	27.3 (11.5; 8–40)	–
Mean years since diagnosis (SD, interval)	12.8 (11.1; 1–39)	–
Recruitment area		
Paris	8	–
Province	12	–
Recruitment method		
Rheumatologist medical consultation	18	
Patient association	2	
Psychological characteristics		
Depression [†] (mean HADS score, SD, interval)	5.3 (3.3; 0–11)	5.8 (3.7; 0–13)
Anxiety [†] (mean HADS score, SD, interval)	7.2 (4.7; 0–19)	8.3 (4.3; 3–17)
Burden ^{††} (mean Zarit score, SD, interval)	–	16.6 (10.7; 0–40)

Notes: No statistical difference was observed between patients and relatives.

*Scores range from 0 to 30; a higher score indicates higher disease activity.

**Scores range from 0 to 60; a higher score indicates higher disease activity.

[†]Scores range from 0 to 21; a higher score indicates anxiety or depression.

^{††}Scores range from 0 to 88; a higher score indicates a high burden.

to come? The [disease's] progression, critical times and at-risk periods. (Patient 7)

... what he should know, maybe he should ... he should recognize the disease completely, without ... any ambiguity. He should know perfectly what treatments are provided and the exact degree of the disease. (Relative 11)

Besides these practical aspects, the participants also said that relatives should have several interpersonal skills: they should be able to offer emotional support and listen to the patient, provide assistance and be careful not to impair the patient's autonomy. The participants also thought that relatives should consider the patient in the same way as before the disease occurred.

When the suffering person is unable to do something specifically ... well he should take the reins. I think in a couple, one has to be able to take over from the other, otherwise it's not a couple. (Patient 3)

Also ... it's rather complicated because ... you have to be present, but not too much. You need to find the right balance. (Relative 16)

Patients and relatives had similar perceptions regarding these three types of expected roles.

Finally, it is noteworthy that some patients and relatives expressed the idea that relatives have a role that they consider is essential.

I think the relative's role is very important. Because it allows oneself to accept much more. (Patient 10)

For us ... that's like we said, it's essential. (Relative 14)

Dyad Relationship

The disease can have an impact on the relationship between patients and relatives, mainly regarding their communication skills.

Many participants described their usual relationship as a partnership, a team, with high complicity and complementarity. Some of them even described themselves as a fusional couple, doing everything together.

I think that ... when we are two people, we are stronger ... each one is a support for the other. (Relative 20)

There were also some special features in their communication in the context of the disease. Many participants said that they could talk about the disease together, although some said they avoided talking about it. In fact, it appeared

that they could talk together about some subjects, whereas others were only approached when inevitable.

Well, for us, it seems essential to share, to talk about [the disease]. (Relative 14)

You know, I get a shot every 23 days now. Well ... pretty often, we spend 23 days without talking about the disease. (Patient 21)

More precisely, regarding patients communicating about their difficulties and needs, most participants reported that even though the patients could talk about them, they did so quite rarely.

Let's say ... if she goes through a tough period, she just ... well, tells me so I understand that she's going through a hard time and ... that's it. (Relative 18)

And I ... don't complain about it so ... (Patient 6)

Even though the patient's problems were said to be perceptible by most patients and relatives, it can be difficult for the relative to understand them, as well as the patient's reactions. This difficulty in understanding was stated by most relatives, but only a few patients.

I understand his difficulties, because they are obvious, they are visible. (Relative 2)

[...] she's not well, but I don't understand why she's not well, because I don't know why. In fact, it's because we don't understand why. We don't understand why the person who ... looks fine, is fine, but after 5 minutes, she can't bear it anymore. When you look at them you get the feeling they're overdoing it. When in fact, I'm sure it's ten times, a hundred times the opposite. (Relative 15)

In fact, many participants also stated that the relative did not express his/her difficulties to the patient, whereas only a few said they did.

So he is ... those difficulties, he won't tell me about them. He won't tell me. Because he doesn't want to ... how can I say it? ... to worry me. (Patient 5)

This lack of communication between the patient and his/her relative can have an impact on their relationship. Indeed, many participants reported some tensions and conflicts.

Let's say that ... I think that between me and her now, the communication doesn't always work well, even if it's there. It's not entirely frozen. Sometimes there are periods that are more difficult. (Relative 3)

[the disease] changed a bit our, our relations. They are less ... they are sometimes ... well, it's my, it's my own fault. They can be more tense. (Patient 8)

Finally, some relatives also said that they had, together with the patient, a positive attitude regarding the disease. This topic was not addressed by any patient.

We're not isolated! But rather ... we try to make the most of the present. (Relative 18)

We think to ourselves Ok, she's going through a rough spell, but it's going to get better. (Relative 9)

Help Relationship

The interviews illustrated whether asking for help or not is a major issue in the patient-relative interaction. Most patients are unlikely to ask for assistance or express a need for help. They prefer to self-manage or at least they start trying to do things and only ask for help if they have no alternative. By asking for assistance, some patients feel they are complaining. Therefore, some patients prefer not to seek assistance, for fear of worrying their relative. However, some patients directly show they need assistance when they assume that their relative will be able to provide it. Some relatives anticipate the patient's unexpressed needs.

But I don't want to ... be demanding all the time. (Patient 10)

I try to think faster than he acts, to be there when ... And it's not good. I have ... I realize it's not always good. (Relative 4)

In accordance with what participants said about the relatives' expected role (part 3.1.), they described the practical assistance relatives actually provided. Relatives take part in the management of the disease, for example by being present at medical consultations, and trying to provide physical comfort or reduce pain. Relatives also often help the patient in his/her everyday life with home mobility or personal care such as washing or dressing. On the whole, relatives tend to compensate for the patients' disabilities.

Yes, for example, if he has some difficulties putting on clothes, things like that, I can do it. (Relative 2)

You know, the technical support too, when I have to do my shots or reminding me to take my medication. I just have the shots, but telling me "you know, you should be careful, I believe it's been some time since we did your last shot" [...]. And helping with the shot [...]. She takes care of that. (Patient 21)

Finally, relatives offer emotional help. They provide compassionate listening and emotional support, and have a motivational attitude to help the patient keep thinking positively. They make themselves available. However, they may sometimes be overprotective with the patient.

[...] the one who's available, who will ... really not make you feel like you're a burden. I think that Emily, she really did make herself available for me, while making me feel it was normal. (Patient 13)

I have to be the driving force. (Relative 6)

Discussion and Conclusion

The study shows that patients and relatives have similar perceptions regarding the relatives' role toward patients with IA: knowledge about the disease, technical skills and interpersonal skills. This refers to self-care and psychosocial skills in TPE. While previous studies have shown the effects of relatives' attitudes on patients' adjustment through quantitative methodologies (self-reported questionnaires), this is the first one to our knowledge to explore specifically the relatives' role in IA management; moreover, from a two-way perspective (patient-relative dyads). The results give insight into the wide-ranging role of relatives, the complexity of patient-relative interactions regarding requests for help and, more generally, in their relationship and ability to share difficulties.

The results show that patients and relatives are conscious of the relatives' role in disease management regarding knowledge and know-how (practical and emotional). Their specific experience and interactions provide more information about these skills. In their view, relatives should know as much as patients about the disease and treatments and have practical skills, especially in pain management and in giving injections. This is probably an important message to deliver to relatives, to make them aware of this need, which can be a need for recognition or for support and safety. Interpersonal skills are also required and it seems important to underline that these are quite complex. For example, participants explained that relatives should always be aware of being present, supportive if needed, but in a balanced way, without impairing the patient's autonomy. This involves a great deal of respect and loving kindness. These results underline the high level of expertise that relatives should have and might explain the psychosocial burden observed among this population in several studies.^{4,7,8}

The results also highlight the challenges faced by patients and relatives in their interactions concerning the

demand for assistance (e.g., patient willing or not to ask for help, relative's anticipation of assistance) as well as difficulties in understanding each other's reactions and problems. The dyads who were interviewed in this study expressed a good relationship. This is in line with the joint approach to managing illness reported by Matheson et al⁸ in couples, in which the partners felt that they worked together as a couple to cope with the effects of rheumatoid arthritis. However, they also expressed difficulties for which interventions might be suggested. Several practical topics could be addressed: recognizing that IA pain and fatigue can cause mood changes and aggressiveness; a lack of communication, whatever the reasons, can lead to tensions; increasing communication skills (e.g., asking whether the patient is sure he/she does not need help instead of deciding he/she should not do something).

Consequently, what could be proposed in TPE "to help patients and their families" as defined by the WHO? First, the patient's family context should be analyzed: is a caregiver, or more generally a relative (maybe more), especially involved in and/or concerned by the IA? If yes, how does the patient describe his/her relationship with the caregiver? What does the patient expect from him/her? Would the patient agree to integrate him/her into TPE? If the patient manages the IA on his/her own, is there anybody in his/her environment who could be involved?

If the patient wants to integrate his/her relative into TPE, the relative's context should also be explored to understand better the difficulties he/she faces, as well as those that both the patient and the relative experience in their relationship. According to the patient's and the relative's needs, personalized interventions should be proposed. As TPE programs often include individual and/or group interventions to work on patient self-care and psychosocial skills, these will need to evolve in order to include work on relatives' skills. Building such interventions could benefit from the techniques used in multifamily therapy.¹⁹ These are group therapies that include several patients with their families. They are especially interesting for working on communication within the family and have been used in chronic pain.²⁰ As most relatives are partners, specific interventions might be proposed for couples. Those should also take into account caregivers' gender.

Several limitations in our study warrant mention. The first is related to the representative nature of the sample. It mainly consisted of participants identified by rheumatologists during their consultations. Most of these patients had been known to them for several years and they had a good therapeutic

relationship. Patients with more chaotic follow-up may have other difficulties in their management of IA and their relationships with relatives. Second, these results concerned mainly couples, as only two relatives were not the partner. Therefore, they should be taken with caution and further studies should investigate the role of relatives who are not the partner. Third, couples taking part in the study had good and long-standing spousal relationships: not only did their relationship “survive” the IA but they were also able to talk about what they experienced together. This may have colored certain dimensions of the analysis. However, even if the relationships were long-standing, difficulties emerged that could benefit from the intervention of health professionals. Finally, for most patients of the sample, the time since diagnosis was over 5 years. The difficulties expressed were thus much less important for those patients and relatives who had found a way to manage the illness.

In conclusion, this study shows that patients and relatives have common needs associated with disease management (information, treatments) and their relationship (how to adjust to each other). Therefore, it seems relevant to propose TPE programs that take into account these different levels of needs. Health professionals involved in TPE will need to be trained to be able to identify these special features and to intervene by taking into account the patient-dyad relationship.

This paper does not present all the themes that came out of the interviews. Other results give insight into the content and format of TPE programs willing to include relatives. They will be presented and discussed in future papers. Nevertheless, further studies are needed to build specific TPE programs that include relatives according to the patients’ and relatives’ needs. They will also need to evaluate their short- and long-term effects on the quality of life of patients and relatives, as well as their disease management and health issues.

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