



Mann, C., & Dieppe, P. A. (2006). Different patterns of illness-related interaction in couples coping with rheumatoid arthritis. *Arthritis and Rheumatism*, 55(2), 279-286. DOI: 10.1002/art.21837

Peer reviewed version

Link to published version (if available):

[10.1002/art.21837](https://doi.org/10.1002/art.21837)

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PDF-document

This is the author accepted manuscript (AAM). The final published version (version of record) is available online via Wiley at <http://onlinelibrary.wiley.com/doi/10.1002/art.21837/abstract>. Please refer to any applicable terms of use of the publisher.

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## **Different patterns of illness-related interaction in couples coping with rheumatoid arthritis**

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Supported by a grant from the Donated Funds of the Royal National Hospital for Rheumatic Diseases, Bath, UK

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## **Abstract**

### Objective

To learn more about the effect of rheumatoid arthritis on couple relationships and how couples manage the illness within their dyad.

### Methods

8 females, aged 31-60, with rheumatoid arthritis (RA) and their partners, and 4 males, aged 43-75, with RA and their partners were recruited from the rheumatology caseload of a hospital in the UK. Interpretative phenomenological analysis was used for data collection and analysis. During semi-structured interviews, couples were asked about the effect of RA on their lives and relationship.

### Results

This study found clear differences in the way that couples managed the illness of one partner and in the nature of their illness related interactions. On the basis of these differences the couples were allocated to one of 3 groups: the shared illness management group (SIM), the ill partner in charge group (IPIC) or the conflict over management group (COM). In the SIM group both partners attended appointments and shared decisions about illness management. In the IPIC group the ill person claimed and was conceded the right to make autonomous decisions about illness management. In the COM group the well partner was dissatisfied with the way the ill person was managing the illness and conflict resulted.

### Conclusions

Heterogeneity exists in the intra-dyad management of RA. Identifying each couple's style of illness management could make medical consultations and education programmes more responsive to the needs and preferences of patients and their partners. Dissatisfaction of either partner with illness management and resulting conflict could be addressed, with benefits for both partners and possible improvement in disease management.

When an individual with a chronic illness is in a couple relationship it is commonly assumed that this relationship will be the primary source of practical and emotional support for the ill individual. However, couple relationships in which one partner has a chronic illness may be severely challenged by the effect of the illness on each partner and by the resulting potential imbalance in the relationship and roles within the dyad (1,2). Rheumatoid arthritis (RA) is a chronic progressive illness in which both partners experience a major impact on their lives. There are unpredictable intense flares of disease activity that result in high levels of pain and disability with the loss of independence in the performance of many normal daily activities. Life plans are disrupted and uncertainty and anxiety is common. Loss is experienced on many levels, necessitating a psychological as well as a physical process of adaptation (3, 4). The partners may approach the challenge of illness together as a shared difficulty and experience mutual support and strengthening of the relationship (2); or, alternatively, go on to develop separate responses to the challenge including different coping strategies, which can be conflicting (5). As a result, existing relationship difficulties are likely to be exacerbated, increasing the strain, while at the same time greater cohesion is enforced by the dependency of the ill partner, which can become intolerable for some couples (2). At the extreme, the couple relationship may be lost.

The strain on the couple relationship affected by illness is significant not only because of the threat to an important source of support but because previous research on dyads has demonstrated that the existence and quality of a couple relationship affect chronic illness outcomes (6). While the dyad is potentially the most significant source of support for the couple coping with illness, it may also, if dysfunctional, be a threat to the ability of each partner to cope successfully (7). Among the studies of couples coping with RA, clear links have been found between marital adjustment, depression, coping and disease progression (8, 9, 10, 11, 12). A stressful couple relationship has an adverse effect on the progression of the illness and on the emotional health of both partners. Absence of spousal support (10), negative interactions such as criticism (11), or the wrong kind of response (13, 14, 15) can all impact negatively on the ability of the person with RA to cope with the illness and may actually increase disease activity and pain and reduce function (12). The well partners may also need support to cope with the effect of the illness on their life. Hegelson (15) concludes that greater attention should be given to the needs of spouses not only because their distress is an important problem in itself but also because spousal distress reduces support given to the ill partner.

The literature suggests a central role for the couple relationship in the management of RA and in coping with its impact but not much is known about how couples adapt to meet the challenges of RA and how they manage its impact on their dyad. In addition to the literature (5, 11, 14, 16), the authors' experience as clinician and therapist indicated the existence of different couple interactions with regard to illness management, which could be obstructive or stressful. If the impact on the couple and the individual way in which each couple manages the illness were better understood this might be of assistance in improving the care of people with RA. The objectives of this study were:

1. To gain information about how couple relationships are affected when one partner has RA
2. To gain information about how individual couples manage the illness.

## **Subjects and Methods**

Local ethical committee approval for the study was obtained.

### **Recruitment**

The sample was drawn from the rheumatology caseload of a hospital in the south-west of England.

The inclusion criteria were:

- a. One partner receiving treatment for rheumatoid arthritis
- b. Both partners over 18
- c. Both partners capable of coherent verbal communication
- d. In a couple relationship of at least 6 months duration, and such that each views the other as their next of kin
- e. No open hostility between the couple evident at time of recruitment

Convenience sampling was used, supplemented by purposive sampling so that the sample would approximate to the age range and gender balance of the RA population. 16 patients gave preliminary consent. However the partners of 3 of these did not wish to be involved and another couple would have preferred a group interview but, as all other participants chose an individual interview, they were not interviewed. 12 couples were therefore included in the study. (For convenience, the partner with RA will be referred to as the ill partner and the other partner as the well partner even though in some cases this partner also had an illness). In most cases (n= 9) the ill partner responded to a leaflet about the study that was given to them as they waited for their rheumatology out-patient appointment. Two couples were recruited after the ill partner was approached by the researcher while he/she was on the ward. A third couple was recruited by a clinical nurse specialist during a clinic visit. None of the couples was currently receiving any intervention or counselling.

### **Demographics**

The sample consisted of 8 females and 4 males with RA and their partners. The ill females ranged in age from 31 to 60 years with an average age of 50 and the ill males from 43 to 75 years with an average age of 60. The well partners ranged in age from 29 to 72 years. Disease severity varied but all cases had been prescribed at least one disease modifying anti-rheumatic drug (DMARD). Illness duration ranged from 1 to 19 years and relationship duration from 2 to 40 years. All the couples were married but the partners in 5 couples were not in their first marriage or couple relationship. Two subjects had already been living with RA for some years when they began their present relationships and three developed RA around the same time as their relationships began or soon after (figure 1).

10 of the ill partners were still of working age and 6 of these were in paid employment, 4 full time. Of the 9 well partners still of working age, 8 were in full time paid employment. The 9<sup>th</sup> partner was no longer working due to her own illness.

## **Methods**

Interpretative Phenomenological Analysis (17, 18) was chosen as the research method for the study. This uses participants' individual perceptions as data, resulting from their experience of the phenomena under investigation, the meanings they ascribe to it and their emotional responses. It was considered particularly suitable for this study because the way in which couple relationships are affected by RA will depend on how couples experience, give meaning to, and respond to the illness emotionally and functionally. The attempt to gain insight into, and represent, the participants' personal experience is inevitably and necessarily mediated by the researcher's own experience and conceptions in an interpretative process. In this case, the researcher's perspective as a couple therapist influenced her probing of possible meanings and areas of interest during the interviews, as well as the interpretation of the data when it was analysed.

When preliminary consent forms had been received from both partners each couple was contacted to arrange the interview which took place at their convenience, either at home (n=11) or in the hospital (n=1). At the time of the interview a further consent form was completed and then demographic data was collected by means of a questionnaire administered by the researcher. Questions were also asked about relationship and family history and attitudes to illness in family of origin. No formal measure of disease severity was used at the time of interview or recruitment, but overall illness severity was informally assessed by participants' account of the illness, observed and described disability, and medication required.

Couples were interviewed together because the researchers were interested in the couple interaction. Semi-structured in-depth interviews were conducted to gather a rich account of the subjects' perception of the effect of rheumatoid arthritis on their lives and couple relationship. Interviews lasted between 70 and 90 minutes, with the exception of one, which was ended after 20 minutes when significant conflict developed between the couple (note 1). A list of topics was compiled by drawing from the literature and the researcher's experience and used as a prompt to ensure that all areas had been covered during the interview (figure 2). This was modified during the course of the research in the light of emerging themes. Subjects were encouraged to talk freely and develop their own areas of interest except when this diverged too far from the effect of arthritis on their life and relationship. No new themes were emerging by the end of the interviews. All the interviews were audiotaped and field notes were made immediately after the interview recording the interviewer's impression of the couple, their relationship and their home.

Each interview was then transcribed verbatim and checked by the researcher against the recording. Every transcript was read several times and examined in detail for themes, which were all noted and arranged into broad categories. During this process several themes emerged which related to the way the couple managed the illness between them and having chosen this focus all the transcripts were examined

again to confirm the validity of the theme and build a clear picture of it. Four other experienced researchers were asked to read one or two of the transcripts each to see if they gained a similar perception of the couple relationship and illness response and to see if they identified any themes that the researcher had missed. One third of the transcripts were checked in this way. Differences were resolved by discussion and no additional themes were identified.

## Results

The different patterns of illness-related interaction, which emerged during this study, were reflected in different models of couple illness management.

### Data analysis

Several domains emerged relating to illness management within the dyad:

- a. Well partner's approval of the way the ill person is managing
- b. Conflict within the dyad around illness management
- c. The ill person's prerogative to decide illness management
- d. Sharing in patient-hood, indicated by use of 'we/our' when talking about illness, and attending medical consultations together
- e. Support given by well partner
- f. The ill person sharing illness information with the well partner
- g. Well partner's knowledge, interest and wish to be involved
- h. Gender of the patient
- i. Severity of illness

The central issue regarding intra dyad management of the illness was who possessed the prerogative to make illness related decisions, including treatment and extent of activity limitation (domain c). Based on this difference, the couples could be placed into 3 fairly distinct groups (figure 3). 4 other domains seemed to have a close bearing on this and so the findings for each couple in relation to these 5 domains are represented in figure 3.

There was evidence in 75% of the sample (n=9) that there was some degree of conflict around illness management and the other 25% (n=3) all gave an example of at least one illness management issue that had caused contention between the partners. The main difference between the '*Conflict Over Management*' (COM) group and the other 2 was whether the well partner felt overall that the ill person was managing their illness badly and attempted to challenge his or her mode of coping with the illness and prerogative to manage it. Three couples fell into this category and consequently were placed in the group (3 of the 4 males with RA fell into this group). Six couples in which the well partner felt that the ill person was managing well and accepted his/her prerogative to decide illness management were placed in the '*Ill Person In Charge*' (IPIC) group. The remaining 3 couples had a sense of shared patient-hood and mostly shared prerogative to manage the illness and were placed in the '*Shared Illness Management*' (SIM) group.

In 7 cases both partners appeared to be satisfied with the arrangement although that did not necessarily mean that there were no areas of conflict. In 3 cases both

partners were dissatisfied with some aspects and in 2 other cases the well partner was dissatisfied.

The detailed findings related to each group follow.

### **The Shared Illness Management (SIM) group**

This group (n=3), in which all three ill partners were female, had a sense of shared ownership of the illness, which went beyond the acknowledged impact on their shared life. There was a sense of mutual support, balance and trust in the relationships. Both partners attended medical consultations, and the pronouns 'we' and 'our' were used in discussing the illness and its treatment. Decisions regarding management of the illness were shared. Any illness-related disagreements were to do with the amount of help the ill partner was willing to ask for or accept.

Female ill partner: I always find it very helpful if [male well partner] is there, because, as I say, I'm nervous and it means there are two of us to try and remember everything that's been said.....And sometimes there are decisions to be made and I would naturally sort of want them to be our decisions

Couple 15

Male well partner: 'We went to see our GP who .... wrote to this hospital and asked if we could come along for a consultation initially which we did'

Couple 1

While this shared ownership approach was clearly experienced as mutually supportive by all three couples, there was a danger of the well partner becoming over-involved. In couple 1, the male well partner was distressed by his helplessness in the face of his wife's pain. She, while appreciating her partner's support, seemed to find his concern and involvement a little excessive and a threat to her identity.

Male well partner: I feel frustrated that I can't do more physically for [female ill partner] around the house, because she won't let me ..... I say "let me do that for you, sweetheart". "I can do it". "I know you can do it, but I'm here, use me". "Don't treat me like a cripple"

Couple 1

In couple 15, the well partner's involvement resulted in considerable burden to him from providing nursing care to his wife and managing her numerous medical appointments and repeat prescriptions alongside his full time employment. However both appeared to take it for granted that he would continue to do this.

Both of these couples talked of the illness management as a battle that they united in fighting against a health care system that could be inadequate.

Female ill partner: 'Four layer bandages seem to be quite a specialised thing to do. So far [male well partner] hasn't been allowed to be taught how to do them .... trying to arrange for [male well partner] to actually have a training session is our next battle that we're in the process of fighting'

Couple 15

In couple 6, the illness sharing was enhanced by the male partner's co-morbidity and they managed both illnesses as a couple, maintaining mutuality and balance in the



relationship. They enjoyed helping each other, which had become part of their bonding, however there was some minor conflict because each wished the other would accept more help.

Female ill partner: 'There are lots of things I would like to do and I can't do but then [male well partner]'s the same with his [illness]..... so we compromise really and just help each other' Couple 6

Male well partner: 'We've both got something wrong with us in that case, that's why me and her do get on probably so well' Couple 6

### **The Ill Partner In Charge (IPIC) group.**

The largest group (n=6) consisted of 5 females and 1 male with RA and their partners.

The relationships in this group were perceived to be well-balanced and satisfactory to both partners in spite of high levels of support given to the ill partner. The group was characterised by the respectful, sensitive and substantial physical and emotional support that was consistently provided by the well partner, sometimes asked for, sometimes without needing to be asked. This support went hand in hand with confidence in the way the ill person was managing the illness. Both partners considered it was the ill person's prerogative to manage the illness, attend medical consultations alone, and make autonomous decisions about the daily activities he/she would undertake based on his/her state of health. Some well partners found this easier to accept than others. The partner of one woman who had had the illness for many years already before their relationship began was in no doubt.

Male well partner: 'It's down to her at the end of the day – if she wants to stop work or she wants to do something or anything that's to do with her illness, it's up to her. To me it's not up to anyone else' Couple 11

The ill person's effort was important to the well partners who all respected their ill partner's attitude and adaptation to the illness, even expressing pride in this.

Male well partner: 'I do think it's important not just to sit back and accept what you've got and get into a routine of doing nothing.....I think for myself that is very important, seeing, you know, effort put in.' Couple 5

Male well partner: 'I think it's very important and it makes me proud that she's, she sort of gets on with things and she tries things although I get angry at times because she does too much. Yeah, I'm quite pleased with the way she's dealing with it. I like her a lot for it, you know, she's doing very well' Couple 14

None of the partners in this group attended medical consultations with their ill spouse. In 2 cases this was not seen as necessary but was not ruled out. In another case the ill partner did not wish her spouse to witness what she might become and was therefore glad that he did not accompany her to the hospital. In the other 3 cases the ill partner would not allow her partner into the consulting room.

Female ill partner: I won't let him come in. I mean I think I'd walk out if he walked in, I feel that strong  
Couple 10

In all 6 of these couples, the ill person shared information from the consultations with his or her partner as he/she considered appropriate. The amount of information possessed and desired by the well partners varied considerably across the sample; 3 of the well partners would have liked access to more information. One felt he had been unsupportive initially, due to lack of knowledge. Another well partner was content to leave it to his wife to educate him about the illness as she saw fit and had no particular wish to know more. He was among several well partners, however, who referred to the way they had learnt about their partner's needs over time and had learnt to accommodate them often without thinking. Adequate information about the illness and good understanding of its effects were clearly important for the provision of support.

Male well partner: 'I found it very difficult to understand and I didn't think it was as serious as what it was. And then as I gradually learnt along the way, it became a bit of an eye opener and I think I became a bit more sympathetic towards her. [...] I used to think at one stage maybe she was pushing it a little bit, you know, and I look back and I feel so guilty about it because I didn't understand it'  
Couple 14

There was a sense of watchful restraint from the well partners because they tried to respect the ill person's independence but held themselves ready to step in whenever needed. This was clearly not always easy and most (n=5) felt there were times when their ill partner should be accepting help that they were avoiding or refusing.

Male well partner: She doesn't tell me if she's having a bad day or she's in a little bit of pain. When she's in a lot of pain she will, and when I notice her hands swelling up.... I'd like to help more without mollycoddling and fussing'  
Couple 10

Understanding of his wife's need for autonomy was expressed by one well husband:

Male well partner: 'She's got to have a life, but she's got to do it her way, and she don't need me to put my opinions on to her'  
Couple 11

Because the well partners were also deeply affected by the illness, a certain amount of trust was involved in allowing the ill person to have control of the illness management. Trust was also required in the other direction and one ill person referred in strong terms to the importance of being able to rely on their partner.

Female ill partner: 'You've got to have somebody who you can lean on, you know, it's not a disease actually that you can have somebody you can't rely on. I mean basically if you can't trust somebody who's going to wipe your bum when you need it because your hands don't work, then they might as well not be there'  
Couple 14

The ill partners all felt that they were able to rely on their spouse but all had a tendency to be reluctant to ask for help, sometimes to an extreme degree, which was commented on by all the spouses except one.

Female well partner: 'You don't like asking for help .... I mean he'll sit here in the evening, and then he'll get up and I'll say, "Where are you going?" "Oh I haven't got a handkerchief", "Well, why don't you ask?"

Couple 12

### **The Conflict Over Management (COM) group**

The 3 couples in this group were all in their original longstanding couple relationships. One couple had divorced over 10 years ago but then recently remarried after one partner's RA developed. Two of these relationships were generally conflicted, one seriously so, whereas the third only evidenced conflict around the illness. The ill person in each case was male. Only one male ill person in the study was not in this group. The main characteristic of this group was that the couple had not achieved a wholly satisfactory means of co-operating around the illness and so the well partner was critical and distrustful of the way that the ill person was coping with their RA. She was experiencing negative impact from the illness that she was not able to control.

Female well partner: 'I know he's in a lot of pain but he doesn't help himself.....He sits there and he feels sorry for himself'

Couple 16

Female well partner: 'Every morning it was 'Oh I ache here and I ache there' and I said to him 'Most people are worse off than you, you know, you have to learn to live with it''

Couple 2

There was a lack of trust involved in the well partners' feeling that the ill person was not doing all he could and a sense of inequity, frustration and even of being deceived. Lack of communication and understanding led to critical feelings about the ill person who in turn did not feel fully supported and was less inclined to discuss the illness with his partner.

Male ill partner: 'She tells me I can do these things if I tried but you see I'm not that way inclined'

Couple 2

Female well partner: 'You don't tell me that you've got a flare up and I know because I can see he's walking a bit strangely or he's changing gear in the car with the wrong wrist or whatever it is.'

Male ill partner: 'The reason that I don't tell you is that I don't want it to restrict what I enjoy doing. I know that if I were to say to you on a Sunday night, "Ow, my ankle's flared up again", you'd then say to me "Well you can cancel that squash court on Tuesday then".'

Couple 3

The importance of communication to reduce conflict over illness management was identified by two people in this group. The well partner in couple 2 found that she

became less critical when she started attending medical consultations with her husband:

Female well partner: 'I find it easier to cope with, knowing more about it now that I go in with him' Couple 2

The ill partner in couple 3 realised that it would probably be helpful to give his partner more information about his condition:

Male ill partner: 'One thing I hadn't really considered before was how me trying to pretend it wasn't as bad as it was, the effect that can have on [female well partner]. I probably need to be more honest with [her] about what I am or aren't suffering at any particular time' Couple 3

### **Discussion**

This was a preliminary, primarily descriptive, study intended to explore how the couple dynamic and the life of the couple was affected by RA. Significant impact on the shared life of the couple was found as expected, but the main new finding was that couples adopted heterogeneous patterns of intra-dyad illness management. We did not set out to study couples' illness management styles specifically and the questions posed were open ones with the intention of identifying issues or difficulties from the couples' perspective that might expose weaknesses in health care provision and warrant further investigation or possible intervention. Previous research has concentrated mainly on specific questions such as how the spouse affects coping (5,11,14), or whether to include the spouse in education programmes (19), or what factors affect the coping ability of the well spouse (8), but the authors were unable to find any qualitative research that seeks to map out from the couple's perspective the impact of this illness on their relationship and shared life. In particular we are not aware of any existing research on different couple styles of illness management and their implication.

One shortcoming of the study is that recruitment was probably biased as a result of the method of sampling, in that couples whose relationship was severely strained or in which the well partner was generally unsupportive or felt to be overburdened would be less likely to spontaneously volunteer for the research. Further research into the effects on couples would probably benefit from some kind of purposive sampling or random sampling in which individuals and couples are directly asked if they would be willing to participate. A leaflet advertising the study which invites them to respond is easy to discount without really considering it as no response is needed. Being directly asked by the researcher or someone else who knows about the study requires a definite answer while still allowing them complete freedom to refuse. In addition their decision can be more informed and considered, as they will have the opportunity to ask questions. Even so it is highly probable that many would refuse, since several of the patients in this study who initially made contact could not be enrolled into the study because their partner was unwilling to participate.

The sample size was limited by resources and the smallness of the sample limits the generalisations that can be made from the data. It may be that other styles of intra-

dyad illness management exist, such as well partner in charge which, due to the means of recruitment, were not identified. Clinical experience indicates the possible existence of this style. A more specific investigation with a larger sample and a more formal means of classifying different styles would yield more information about the prevalence of each and their advantages and disadvantages.

The data may also have been limited by electing to interview the couple together. For example, the male partner of one very distressed ill person did not reveal any of his own feelings and spent the interview trying to reassure his wife. However there were benefits in creating the opportunity for couples to have a dialogue with each other about the effects of the illness and several commented that they had learnt something new from listening to their partner. It also made it possible to gain a sense of the general couple interaction and balance of power in the relationship.

### **Future research**

Although the study has identified the existence of different styles of intra-dyad illness management, their significance requires further investigation. The finding that conflict in varying degrees associated with illness management was common suggests that this is an important area. Three basic patterns of illness related interaction were found, none of which were entirely without strain. The advantages and disadvantages that were indicated by the study participants in each group are summarised in figure 4 but quality of life and functional measures could be applied to investigate this more thoroughly. It was clearly difficult for the well partner to have relatively little control over circumstances that affected him or her so much. This concurs with findings by Trief et al (20) who found that a high potential for conflict exists in couples living with diabetes because of conflict between the ill person's need for independence and the well partner's anxiety about the consequences of poor disease management.

More needs to be known about what predisposes dyads to adopt a particular illness management style and the benefits and difficulties associated with each style. Although there were evident strains, the couples had on the whole adopted an illness related interaction that was consonant with their overall couple relationship dynamic and all but 2 of the relationships were functioning satisfactorily. A study that compared the illness management style to scores in the Dyadic Adjustment Scale (22) might reveal some interesting correlations particularly with regard to the subscales of consensus and cohesion. Other questions are whether choice of management strategy is a response to illness severity and anxiety, or the result of other factors, such as co-morbidity of the partners, or the timing of the illness onset in relation to the relationship. It would be interesting to explore the relationship of illness management style to pre-existing relationship characteristics such as communication and balance of power, and to other pre-existing factors such as ill person's degree of self-efficacy and family background. For instance, many of those in the IPIC group described an upbringing that pre-disposed them to self-reliance. The fact that all the ill people in the COM group were male suggests that there may also be gender differences that affect intra-dyad illness management.

Although more needs to be known, there are implications from the findings of this study for the management of medical consultations, not least because of the strong and sometimes conflicting feelings of the couple about attendance. While the wishes of the ill partner have to be respected the needs of the well partner should not be ignored, both for their own sake and because of the consequences for illness management. An important question is whether a couple is satisfied and functioning well with the style of illness management they have adopted. Asking patients about how their partners are responding to the illness or offering a consultation to the partner might help to identify difficulties the couple are having with intra-dyad illness management and provide an opening to explore their illness management style and whether it should be modified by, for example, inviting the partner into consultations or excluding him/her and perhaps offering a separate consultation to the partner. An important next step therefore might be to develop some formal means of assessing couples' illness management style. This could perhaps take the form of a brief questionnaire that combined a measure of relationship satisfaction and conflict with some questions about intra-dyad illness management, which could inform clinicians' management and educational programmes and gauge the need for intervention. The ill person's coping might be undermined by a partner who wishes to have a great deal of involvement with the management of the illness. Conversely, a partner who is feeling isolated and sidelined from the management might be less than fully supportive and even openly critical, resulting in conflict and increased stress for both. Couples in the COM group are clearly at greater risk of relationship breakdown and appropriate intervention could be offered after assessment of the cause of the conflict. Similar issues arise in the provision of education sessions and may be one reason why including well partners in group education has been found to be of variable benefit (19). Well partners in the IPIC group might benefit from individual or group education sessions without the ill partners, whereas couples in the SIM group would probably prefer shared disease management education. Allocating patients and their partners to sessions that suit their illness management style might improve uptake and outcomes.

Many researchers have pointed to the importance of considering the couple relationship and what part it is playing in the management of the illness (5, 6, 16, 19, 20, 23, 24, 25). This study indicates one possible approach and serves to generate some of the questions that need to be considered if couples affected by RA are to receive the support they need to optimise the management of the illness.

Figure 1

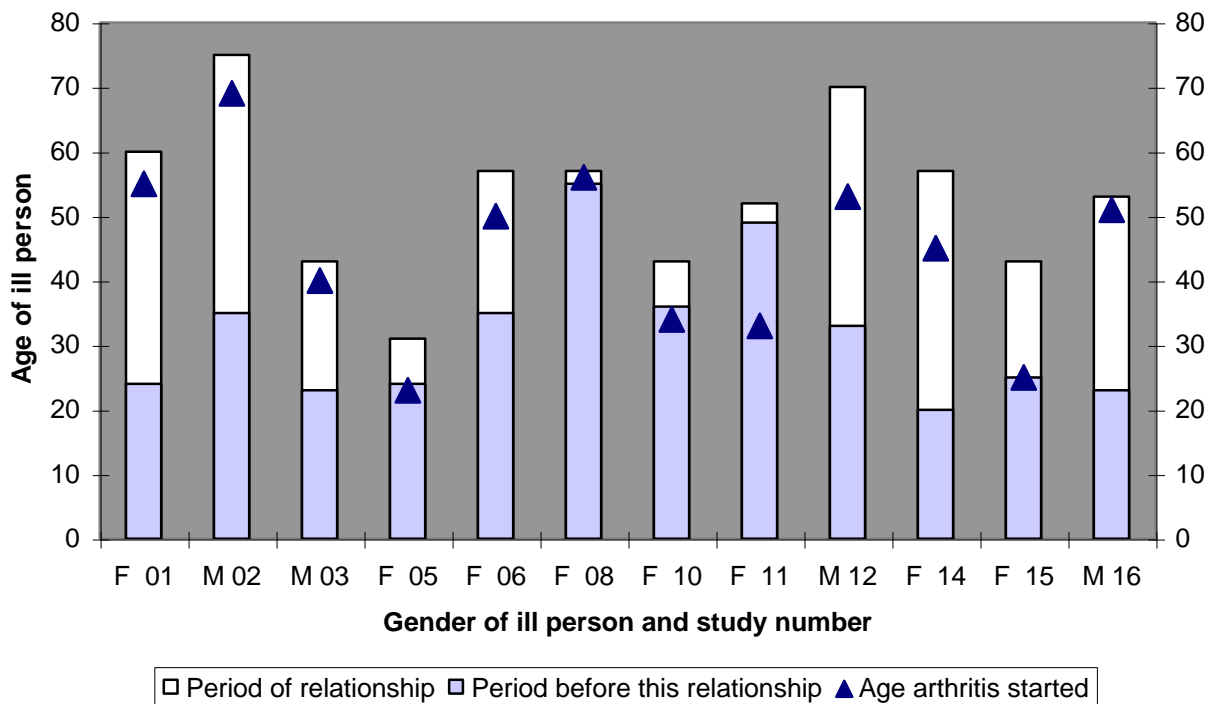


Figure 2

Broad questions	Interviewer's topic check list
<p>Please tell me the story of your illness</p> <p>How do you feel it has affected you as a couple?</p> <p>How has it changed your relationship? (if at all)</p> <p>How much do you feel you share the illness?</p> <p>How do you manage the need to give/receive help?</p> <p>What areas of conflict are there? (if any)</p> <p>How do you feel you have adapted to the illness?</p> <p>How well do you feel your partner understands what it's like for you?</p> <p>How well do you feel you understand what it's like for your partner?</p> <p>How much do you feel the illness has taken over your life?</p> <p>What benefits, if any, have there been as a result of the illness?</p> <p>What support do you receive from outside the relationship?</p> <p>What additional support or help, if any, would you wish for?</p>	<p>Diagnosis, emotional reactions, treatment, physical consequences</p> <p>Effect on roles, relationship, life style, work, sex, social life, family, financial, making plans</p> <p>Roles, balance, dependency, sex</p> <p>Information sharing, attendance at medical consultations, decision making, emotional burden</p> <p>Solicited help, unsolicited help, the need to ask for help</p> <p>Coping styles, modification of lifestyle</p> <p>Empathy, communication, support</p> <p>Family, friends, health care professionals</p>

Figure 3

	Gender of ill person	Well partner thought ill person managing well	Any conflict or disagreement over managing illness	Prerogative to manage illness	Shared patient-hood - use of 'we' and 'our'	Group
RAC1	F	Yes	Yes	Shared	Yes	SIM
RAC2	M	No	Yes	Contested	No	COM
RAC3	M	No	Yes	Contested	No	COM
RAC5	F	Yes	No	Ill person	No	IPIC
RAC6	F	Yes	Yes	Shared	Yes	SIM
RAC8	F	Yes	Yes	Ill person	No	IPIC
RAC10	F	Yes	Yes	Ill person	No	IPIC
RAC11	F	Yes	No	Ill person	No	IPIC
RAC12	M	Yes	Yes	Ill person	No	IPIC
RAC14	F	Yes	Yes	Ill person	No	IPIC
RAC15	F	Yes	No	Shared	Yes	SIM
RAC16	M	No	Yes	Contested	No	COM

SIM (Shared Illness Management) defined by shared patienthood and prerogative

COM (Conflict Over Management) defined by criticism of ill person's management and contested prerogative

IPIC (Ill Person In Charge) defined by well partner's confidence in ill person's management AND well partner accepting ill person's prerogative to manage illness

Figure 4

	Advantages	Disadvantages
SIM	<ul style="list-style-type: none"> <li>Allows well partner to share responsibility and burden</li> <li>Reduces burden of his anxiety and distress on ill person</li> <li>Well partner less likely to blame ill person for poor management</li> <li>Negative feelings can be directed outwards towards health care instead of towards each other</li> <li>Combined forces in dealings with health services</li> <li>Well partner can share patienthood and also receive care</li> <li>Mutual support</li> </ul>	<ul style="list-style-type: none"> <li>Loss of autonomy for ill person</li> <li>Some couples might not tolerate high degree of cohesion required</li> <li>Lack of privacy for ill partner</li> <li>Increased burden for well partner, leading to overburden and 'role strain' (21)</li> </ul>
IPIC	<ul style="list-style-type: none"> <li>Ill partner retains control over fundamental aspect of their life</li> <li>Ill partner retains autonomy, self-respect and privacy</li> <li>Mutual trust may strengthen relationship</li> <li>Well partner can be less burdened by illness and life less affected</li> <li>Ill person feels they are making a contribution by taking responsibility for illness</li> <li>Ill person benefits from partner's support</li> </ul>	<ul style="list-style-type: none"> <li>Well partner, who is also affected, may feel isolated, disempowered and frustrated</li> <li>Stress for well partner due to lack of control</li> <li>Well partner may become distrustful and critical</li> <li>Well partner may be insufficiently informed leading to over-anxiety or lack of understanding of partner's needs</li> <li>Well partner may lack support</li> </ul>
COM	<ul style="list-style-type: none"> <li>None identified</li> </ul>	<ul style="list-style-type: none"> <li>Stressful for both partners</li> <li>Negative impact on disease management</li> <li>Potential loss of relationship</li> </ul>



#### Note 1:

After the interview was terminated the interviewer continued discussion with the couple to address the conflict and to clarify whether they felt this was caused by the interview, which the couple denied. The researcher offered to discuss possibilities for help with their relationship and did not leave until she was assured that the couple could cope with the situation and were not experiencing undue stress that was not pre-existing. The researcher subsequently wrote to the couple repeating the offer to discuss with them any issues that might have arisen as a result of the interview and possibilities for accessing help to address their difficulties. No response was received.

#### Acknowledgements

We would like to thank all those who volunteered to participate in this study for giving their time and being willing to talk about their experiences. We are grateful to Rachael Goberman-Hill, Kav Vedhara, Jane Carter, Candy McCabe, Jenny Lewis, David Blake, Chris Eccleston, Ed Keogh, for helpful discussions and to Lucie Byrne-Davies, Charlotte Paterson, Candy McCabe, Louise Chambers for reading and discussing transcripts. We gratefully acknowledge the financial support from the Donated Funds of the Royal National Hospital of Rheumatic Diseases and are also grateful to the UK Medical Research Council for support (Paul Dieppe)

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