

Main article

Patient priorities of care in rheumatology outpatient clinics: A qualitative study

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Abstract

Objective: To provide more understanding of what rheumatoid arthritis (RA) patients want and need from an outpatient visit.

Methods: 25 patients who experienced care in a nurse practitioner clinic ($n = 10$), junior doctor clinic ($n = 9$) or consultant clinic ($n = 6$) in a large teaching hospital in West Yorkshire were interviewed about their perceptions and experiences of care. Interviews were approximately 1½ hours in duration and were carried out in a neutral environment by a research nurse. Interview data were subjected to atheoretical content analysis, which resulted in the identification of emergent themes.

Results: Five main themes emerged from the analysis of interview data: 1) patients want to be communicated to clearly and effectively and value positive relationships with practitioners. These help to give patients confidence in the care they are receiving; 2) patients want to feel in control of their condition and tend to refuse interventions as a way of gaining control; 3) patients want to be given clear explanations during consultations, and want information in oral and written forms; 4) patients want to be able to access practitioners between scheduled appointments as a way of gaining reassurance; and 5) patients want to feel valued by society through having their difficulties appreciated and understood by others.

Conclusion: This research adds to the body of evidence on what patients want from their rheumatology care, and each theme has clear implications for future practice. Copyright © 2007 John Wiley & Sons, Ltd.

Key words: Patient priorities, outpatient care, qualitative research

Introduction

Rheumatoid arthritis (RA) is an unpredictable, incurable chronic disease. A range of interventions are required to manage the physical symptoms of the disease, and these focus on the relief of symptoms, the preservation of function and the prevention of structural damage and deformity (Hill and Ryan, 2000). There are also a number of psychological and social aspects of the condition which affect patients' well-being. For instance, the symptoms of RA interfere with the normal activities of daily life (work, leisure activities, caring roles), there is a great deal of uncertainty associated with the treatment and progression of the disease, and monitoring procedures further disrupt daily life (Hill, 2006). Management issues therefore also include the maintenance of a lifestyle that is acceptable to the patient, and the reduction of psychological distress.

Because the management of RA is so wide-ranging, a multidisciplinary approach to patient care has been advocated by many (Madigan and FitzGerald, 1999). The Arthritis Research Campaign (2003) information booklet on RA highlights the importance of patients playing an active role in the multidisciplinary team, and describes the patient as 'the most important member of that team'. Patients playing a key role in the management of their own diseases have also been the subject of a considerable amount of research, both within the field of rheumatology (Doherty and Dougados, 2001; Sarzi-Puttini et al., 2005) and beyond (Buck and Morley, 2006; Moser et al., 2006), and this is beginning to have an impact on health care policy. For instance, supporting self-care is one of the key aspects of the NHS and Social Care Long Term Conditions Model (2005).

With the increase in patient-centred models of care, there has also been an increased focus on patient satisfaction, which has the power to inform both policy and practice. Rheumatology research has tended to address patient satisfaction quantitatively rather than qualitatively, with attention being paid to designing, validating and using quantitative measures such as questionnaires (Bera Louville et al., 2003; Clark et al., 2004; Hill, 1997). Although these measures often address many different areas of patient satisfaction, such as the provision of information, communication skills and competence, measurement tools do not generally have the flexibility to capture the full range of factors which influence satisfaction. Avis et al. (1997) identified the problems with measuring patient satisfaction quantitatively, such as a tendency to construct measures based on providers' assumptions, rather than patients' experiences. More recently, less structured, qualitative approaches have begun to be adopted, with authors beginning to make the link between patient satisfaction and patients' priorities and experiences (Arthur and Clifford, 2004; Carr et al., 2001; Carr et al., 2003). In particular, it is beginning to be recognized that patient satisfaction cannot be measured without some

understanding of the priorities and expectations which patients have for their care (Arthur and Clifford, 2004).

The research study reported here aimed to provide an understanding of what RA patients want and need from their outpatient care. We looked at the discussions between these patients and an interviewer about the care they had received from outpatient clinics to draw conclusions about their main priorities and to propose ways in which these could be met by outpatient care.

Patients and methods

Between 1998 and 2001, 80 patients were recruited to a randomized, controlled trial to compare the outcomes of patients with RA attending a rheumatology nurse practitioner clinic with those of patients attending a junior hospital doctor's clinic. In 2001, additional funding was obtained to carry out an interview study with a sample of these patients. A sample of 19 participants was recruited by a research nurse (RT) as they were approaching the end of the randomized controlled trial. These participants were self-selecting, as they were the only patients remaining on the trial at the time of recruitment. All of the patients who were approached agreed to participate. A further six patients who had not taken part in the trial but were under the care of a rheumatology consultant were recruited opportunistically in outpatient clinics. All participants were seen in the outpatient department of a large teaching hospital in West Yorkshire. Ethical approval for the study was granted by the local health authority research ethics committee. Approximately five months after agreeing to take part, participants were contacted by telephone and provided with more information about the study and an opportunity to ask questions. A written information sheet was sent to each participant, and informed consent was obtained. Of the 25 participants, 72% were women and all had a diagnosis of RA according to American College of Rheumatology criteria (Felson et al., 1993). Their ages ranged from 37–76 years (median 55 years), their disease duration from 2–32 years (median 13 years) and their full-time education from 8–15 years (median 10 years).

Audiotaped interviews, lasting approximately 1½ hours, were conducted by one researcher (RT) and took place in a non-clinical setting within the teaching hospital. The interviews were structured and were primarily designed to elicit details from participants about their perceptions of the care they had received during the randomized controlled trial. The main aim was to discover whether there were any differences between the perceptions and experiences of patients who were seen by the nurse practitioner compared with those seen by the junior doctor. The interview schedule was developed in conjunction with a nurse practitioner, junior doctor and consultant rheumatologist, who all provided information about their treatment

interventions when in consultation with an RA patient. The interview schedule was reviewed and revised and was then piloted with six RA patients. In the final interview schedule, questions were divided into five main areas: structural/organizational questions, relationship questions, technical questions, RA-specific questions and comparison questions. More specifically, questions included:

- Would you like to see the same member of staff at each visit or would you prefer to see different members of staff?
- Did the person you saw appear to appreciate your problems with your RA?
- Do you know what causes RA?
- During the study, did the person that you saw speak to you about preventing further damage to your joints?
- How do the study visits compare with your clinic visits in the past?

Early on in the data analysis process, it became clear that despite participants being questioned about their experiences of outpatient care during the 12-month study, they did not restrict their comments to this time frame. Participants frequently discussed their experiences both prior to and following the 12-month period. For this research, we focused on these broad-ranging discussions, rather than on participants' direct responses to individual questions. In this way, we were able to identify the aspects of participants' outpatient care and disease management which were most important to them.

The audiotapes were transcribed and downloaded in NVivo (2002), a qualitative data organization/coding software package. Four randomly selected interviews were analysed atheoretically by two researchers. Transcripts were coded for content, and descriptive labels were applied to key phrases. The two researchers compared and contrasted their analyses of the four interviews and agreed on a set of eight labels, or codes. A project codebook was created to list the codes and their definitions, and this was refined following further coding by both researchers. Inter-coder reliability was carried out on one further randomly selected interview, which showed an overall reliability of 70%. All remaining coding was carried out by one researcher (VW). As coding progressed, the researcher began to make links between the codes, and from these, key themes began to emerge. These are summarized in the following section.

Results

From the qualitative interviews, six themes emerged. These were:

- Patients want to be communicated to clearly and effectively, and value positive relationships with practitioners;

- Clear communication and good relationships help to give patients confidence in the care they are receiving;
- Patients want to feel in control of their condition and tend to refuse interventions as a way of gaining control;
- Patients want to be given clear explanations during consultations, and want information in oral and written forms;
- Patients want to be able to access practitioners between scheduled appointments as a way of gaining reassurance;
- Patients want to feel valued by society through having their difficulties appreciated and understood by others.

The demographic details of the participants are shown in Table 1.

TABLE 1. The gender, age and disease duration of participants			
Patient	Gender (M/F)	Age (years)	Disease duration (years)
1	F	64	32
2	M	46	4
3	F	44	20
4	F	46	6
5	F	57	16
6	F	68	2
7	F	63	5
8	M	37	4
9	F	72	13
10	M	61	23
11	F	55	18
12	F	43	13
13	F	48	20
14	M	55	13
15	F	50	7
16	F	52	24
17	F	64	17
18	F	71	30
19	F	42	8
20	F	39	11
21	F	76	20
22	M	74	17
23	F	66	20
24	M	55	10
25	M	74	19

Theme 1: Patients want to be communicated to clearly and effectively, and value positive relationships with practitioners

All of the patients who were interviewed discussed their relationships and communication with their practitioners. The latter included nurses and doctors. They particularly valued clear explanation (19 patients), being able to lead the discussion during appointments (18 patients) and, above all, being listened to during appointments (20 patients). The value that they placed on these things was especially apparent in the way in which they discussed their negative experiences in outpatient clinics, as shown here:

. . . you do get, now and again, the odd time when you just think 'did they hear what I said?' You know, it was almost as if they haven't heard what you've said, as if it wasn't a problem which, to you it is . . . it might seem minor to somebody else, but when you're living with it, it's a different ball game . . . (Patient 15)

Positive relationships with practitioners were important to participants, and these seemed to be based on approachability and empathy. The comments which participants made about positive relationships largely concerned the particular personality traits of practitioners, and did not seem to relate to specific, learnable communication skills, as in this case:

I felt that she was very human and very understanding. You could talk to her as a friend. (Patient 5)

Theme 2: Clear communication and good relationships help to give patients confidence in the care they are receiving

Participants frequently discussed having confidence, or feeling secure, in their practitioners (23 patients)

Well, immediately after the first visit, I felt, like I say, very relaxed, I knew I was being dealt with by competent people that knew their jobs thoroughly and I knew I was at liberty to ask anything I liked, which is very reassuring. (Patient 5)

This confidence was a theme which was closely related to both communication and relationships. For instance:

I've got a lot of confidence in him, gradually I think that's over the years . . . if you see the same familiar face you feel more that you're not being pushed around from one to another. (Patient 20)

Theme 3: Patients want to feel in control of their condition and tend to refuse interventions as a way of gaining control

Participants frequently focused on retaining control of their condition (22 patients). They talked about soldiering on, working things out for themselves, managing without pain medication and refusing interventions such as surgery. Many participants saw that they could be in control of their condition by being in control of their own medications. This was particularly true of pain relief medication, which they felt often represented their lack of control. An example of this kind of mindset can be seen here:

I just don't like taking them, I just don't like taking tablets . . . I think it's just a way of giving in, I just feel as if I'm giving way to things . . . It's like admitting a weakness to me. (Patient 18)

Retaining control of their condition by refusing interventions and altering medication dosages has a potentially negative impact on a patient's condition. Many participants recognized that interventions and medications were important to their well-being, and reported positive outcomes following appropriate treatment. Despite this, they continued to be negative about the need for interventions. This is illustrated well by one participant, who clearly identified that the medication had 'got me well' but admitted that 'I've always been trying to reduce the drugs that I take' (Patient 12).

Theme 4: Patients want to be given clear explanations during consultations, and want information in oral and written forms

Participants were questioned about their experiences of information-giving in clinic settings. The most frequently discussed form of information-giving was 'explanation' (19 patients), and this related to test results, medication and self-management techniques. Participants appeared to be distressed by not receiving explanations and adequate information, but the type of information that was required varied according to participants' own concerns. For instance, one participant was particularly concerned about self-management techniques:

But nobody will tell me what amount and what proportion and if you're walking and you feel tired should you push yourself or should you immediately rest. And that kind of thing you see, which I've no idea about. And I can't find out, anybody that will tell me that. (Patient 18)

Participants reported being proactive in their search for information and discussed reading leaflets, talking with friends and relatives, and searching written media such as newspapers and magazines. However, they appreciated receiving oral

explanations from their practitioners, and felt that these should supplement written information, with one participant pointing out that: 'I understand the written word but not always to that extent' (Patient 9).

Theme 5: Patients want to be able to access practitioners between scheduled appointments as a way of gaining reassurance

During interviews, all of the participants were asked about their ability to access practitioners between scheduled appointments. Their responses suggested that having such access was particularly important to them, as shown here:

I know that if I have a problem I can ring up and make an appointment sooner, but I can just come every six months just to know that I'm not going to be put on the scrapheap . . . (Patient 20)

Although the majority of participants (18 patients) clearly viewed having access to practitioners between appointments as an important part of their outpatient care, what is more interesting is their rationale for such access. Frustration, apprehension and fear of the future were particular characteristics of participants' narratives. As one participant said:

I used to go along and . . . a lot of people who went to the group were really quite disabled and it used to upset me and I used to come home, and it was on my mind all the time that that's how I would be. (Patient 3)

Having access to practitioners between appointments appeared to be valued by participants as a way of coping with such apprehensions. Specifically, access to practitioners was seen as a way of gaining reassurance and support. For instance, this participant appreciated simply knowing who to turn to in the case of a problem:

I think knowing that there's somebody, knowing that if I do have a problem there's somebody, somewhere within the health service that I can telephone and ask for help or assistance or an explanation. I think, just knowing that that facility's there is enough and that is important to me. If I didn't know where to turn, if I didn't know who to go to, then I think I'd have a problem. (Patient 16)

Theme 6: Patients want to feel valued by society through having their difficulties appreciated and understood by others

Participants frequently discussed their sense of personal and social value during interviews (22 patients). Many of them experienced frustration and distress when their condition was not appreciated by others, commenting that 'it's a pity you can't

have it written on your face' (Patient 1). In many cases, this feeling of not being understood contributed to participants' low sense of personal value. In some cases, their personal value was also affected by feeling 'like a social outcast' (Patient 5).

The frequency with which participants discussed not being understood and not being valued suggests the importance that they place on having their difficulties appreciated and understood. This sense of being understood was not only related to society in general, but also to clinic situations, as shown here:

. . . presumably the consultants are told by every single patient that they are incredibly tired, so they then say to other people, well of course you'll be tired. You know, you don't know whether they're really convinced about this! (Patient 19)

This comment also suggests that having difficulties appreciated by practitioners may help to give patients confidence in the care that they receive.

Discussion

Although this study was originally designed to elicit details about patients' experiences and perceptions of the care they received during the randomized controlled trial, participants were keen to discuss their experiences across the entire duration of their disease. This openness contributed to the refocusing of the data analysis on patients' priorities for their care. In addition, research has clearly shown that it is patients' underlying preferences and assumptions which inform their experiences of and satisfaction with care (Avis et al., 1997) and that it is difficult for them to differentiate clearly between alternative types of clinic or practitioner (Long et al., 2003). The present study supported the latter concept, as the broad issues discussed by participants were generic and independent of the practitioner seen.

The individuals in this study expressed a wide range of priorities for their outpatient care, from clear and adequate communication to being understood by others. As might be expected, participants' priorities were largely individual and were related clearly to their own particular circumstances. However, it was possible to divide these individual priorities into six broad themes, which most clearly reflect the overarching desires and needs of this group of patients.

First, the importance which participants placed on positive relationships and good communication with their practitioners (Theme 1) confirms previous research showing these to be main priorities for patients (Arthur and Clifford, 2004; Bensing, 1991; Carr et al., 2003; Ong et al., 1995). Obtaining clear explanations, being able to lead discussions and being listened to were aspects that were most highly prized by participants during their consultations. Indeed, the most common causes of complaints were not being listened to and not being given clear, understandable explanations. Although there has been much research and development in

communication training for practitioners (Beckman and Frankel, 2003; Lawson, 2002), what constitutes a patient's 'positive relationship' with their practitioner is less clear. These participants seemed to focus on aspects of their practitioners' characters which were difficult to quantify, such as approachability, openness and having a friendly demeanour. As these traits are less learnable than other communication skills, 'training' practitioners to develop positive relationships with their patients may be a considerable challenge. However, if a positive relationship with their practitioner is one of the most important things to patients, it is a challenge worth taking up.

Second, participants' discussions and explorations of communication and interpersonal issues highlighted the relationship between these and the degree of confidence which patients have in their practitioners and their care. In particular, there seemed to be a correlation between participants' experiences of positive relationships, good communication and continuity and the trust or confidence which they had in their care. Although continuity of care is largely an organizational issue (often constrained by time and resources), good communication and positive relationships can be focused on by individual practitioners.

Third, participants' experiences of outpatient care did not necessarily inform their attitudes towards certain aspects of their care. This was particularly pronounced in relation to Theme 3 – retaining control. It would seem as though these individuals were exercising control over their condition in negative rather than positive ways, by refusing medication and other interventions, even when they recognized them as beneficial. This attitude is a major concern to health care professionals, particularly in the field of rheumatology, and it is something which compliance research has sought to understand for some time (Donovan and Blake, 1992; Sale et al., 2006; Vermeire et al., 2001). This study suggests that patients need to have their own mechanisms of retaining control of their condition, but that these need to be positive, rather than negative.

Fourth, being provided with oral and written information (Theme 4) and having access to practitioners (Theme 5) emerged as key desires of these participants. It is possible that as well as both providing reassurance and acting as coping strategies, having access to practitioners and being provided with clear information enables patients to make choices about their treatment and disease management, thus helping them to retain control of their condition.

Finally, being valued and having their difficulties appreciated and understood were particularly important to these participants. Rheumatology patients' stigmatization and feelings of exclusion from society have been explored by a number of authors (Mahat, 1997; Murphy et al., 1988; Plach et al., 2004). These participants were no different, but in addition to discussing their feelings of self-worth in relation to society in general, they also discussed their need to feel valued and under-

stood during outpatient consultations. This suggests that approaches which treat the patient as an individual and communicate empathy and understanding should be utilized within outpatient care.

Limitations of the study

The main limitation of this study was the initial use of a structured interview to assess participants' perceptions of the differences between junior doctor and nurse practitioner-led clinics. However, valuable data regarding their perceptions of outpatient clinics as a whole was gathered. Other limitations include the narrow geographical area from which participants were recruited and the age of the interview data. (i.e. over 5 years)

Conclusion

This study has served to add to the body of evidence on patients' perceptions and priorities for rheumatology care. There are a number of important messages that emerge from this study. First, forming good interpersonal relationships and communicating well should be a key priority within outpatient clinics. These help to form the basis of patient confidence in their outpatient care. Second, patients should be provided with the opportunity to take control of their condition, but the provision of information, access and other positive control mechanisms should take individuals' perceptions and priorities into account. Third, patients should be provided with clear explanations during outpatient consultations, and information should be provided in both oral and written forms. They should also be given appropriate methods of accessing practitioners between scheduled appointments. These measures help to provide reassurance, as well as confidence, in their care. Finally, feeling understood and having their difficulties appreciated by society at large was particularly important to patients, suggesting that treating patients as individuals and seeking to understand difficulties should inform the ethos of outpatient care.

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