

General practitioner and specialist care: the perceptions of people with rheumatoid arthritis

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Objective: The care of patients with chronic diseases such as rheumatoid arthritis is increasingly shared between primary health care and hospital specialist teams. Studies that have informed guidelines for the shared care of patients with rheumatoid arthritis have not included patients' perceptions and preferences. The objective of this study was to explore the experiences and views of patients with rheumatoid arthritis concerning the clinical care they had received from general practitioners (GPs) and specialist hospital doctors.

Design: Semi-structured interviews analysed using grounded theory techniques.

Setting and Participants: A purposeful sample of twelve people receiving clinical care from specialist rheumatologists and GPs. All participants had received a diagnosis of rheumatoid arthritis at least two years previously.

Results: Most participants valued regular review by rheumatologists highly, and looked to them for help with all aspects of their arthritis care. They felt that specialists had greater knowledge concerning disease management than GPs, but both groups of doctors were similarly empathic. The GPs' role was perceived to be important mainly in early diagnosis and first referral to the hospital specialist but less so in the provision of continuing care or help with psychosocial issues. Participants valued the accessibility of GP services. Advice from any source about aids and welfare benefits was often haphazard.

Conclusions: People with rheumatoid arthritis prefer to have regular contact with a rheumatologist rather than obtaining care for their arthritis mainly from their GP. This has implications for the move from secondary to primary care.

Key words: rheumatoid arthritis; specialist/secondary care; general practitioner/primary care; patient/user perceptions/views; quality of care

Introduction

The management of chronic illness presents a challenge not only at an individual level as patient and family experience the consequences of disease at first hand, but also for those concerned with the effective use of health and social services. The purpose of this project was to explore the experiences

and views of people who have one such illness, namely rheumatoid arthritis (RA) with respect to the appropriateness of the setting in which their clinical care was delivered.

Recently, attention has focused on the relationship between hospital outpatient and primary care services for people with chronic illness. The term 'shared care' has evolved to describe the situation where patients consult both hospital-based specialists and general practitioners (GPs) for management of the same illness (Pritchard and Hughes, 1995). A number of factors favour a move to greater management within a primary care setting,

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for example long hospital waiting lists, crowded outpatient clinics, increasing accessibility to x-rays and blood tests, the employment of practice nurses who have specific training in chronic disease management and the perceived cost effectiveness of care delivered in the community. Moreover, as suggested by Pereira Gray (1994), there is a perception amongst GPs that primary care is the most appropriate setting for long term chronic illness management.

It needs to be stated, however, that long-term chronic conditions are best managed principally by multidisciplinary primary health care teams who know the patient and to whom the patient can relate as a person, simply because they do involve regular checks. It is best for them to be provided as close as possible to patients' homes, . . . (Pereira Gray, 1994).

However, the likely setting for chronic illness management currently differs according to disease. For example, people who have diabetes and asthma are typically cared for within primary care whilst people who have RA and inflammatory bowel disease often remain under the continuing care of a hospital specialist. For the latter group the role of the primary care team is unclear (Memel, 1996).

Rheumatoid arthritis has a prevalence of 50-60/10 000 people and is a disease of variable severity and disability, with an onset often in middle age (Silman and Hochberg, 1994). It causes pain and disability, and biographical disruption as patients try to adjust to the uncertainty of the disease (Wiener, 1975). Although the disease is incurable, there is evidence that medication can decrease the progression of the disease (Scott *et al.*, 1998), and guidelines have been developed to enhance the effectiveness of shared care (Primary Care Rheumatology Society, 1996). However the roles of specialist and GP remain unspecified. For instance, where should prescribing responsibility lie and should the hospital based rheumatologist focus on disease management leaving functional, social and psychological issues in the domain of the primary care team?

The typical pattern of rheumatology care in the UK is that a hospital medical specialist (rheumatologist) routinely sees patients with RA every few months, but this is currently under review, and a recent trial explored shared care

involving patient initiated follow up, whereby GPs routinely manage their RA patients, but they and their patients have rapid access to specialist services in times of need (Hewlett *et al.*, 2000). Some rheumatology units have explored the use of rheumatology nurse practitioners (Hill *et al.*, 1994). It is not only professional groups that are interested in doctors' roles in the management of RA. The British League Against Rheumatism have audited and published standards of care for both GPs and hospital specialists (Rowan *et al.*, 1997), and many self help books for people with arthritis discuss the role of the different doctors (Holroyd, 1992). There is increasing recognition that the planning of health services needs to incorporate users views (Jordan *et al.*, 1998) but hitherto studies have not examined in detail the experiences and views of people with rheumatoid arthritis.

Methods

Study design

The central aim of the study was to uncover the experiences and views of individuals who have a range of experiences concerning clinical care for RA. The design involved the conduct and analysis of semi-structured interviews using grounded theory techniques. The local research ethics committees approved the study.

Participants

Participants were recruited from the outpatient clinics of four rheumatologists at two Bristol hospitals over a three month period. They were recruited either by a research nurse when they attended the clinic or by a letter sent to their home from their rheumatologist. The study was limited to patients with diagnosed rheumatoid arthritis for two or more years, as the needs are different for newly diagnosed patients (Scott *et al.*, 1998). People having any involvement in a concurrent trial of shared care at one of the hospitals (Hewlett *et al.*, 2000), or that were patients registered at Memel's general practice were excluded. A purposeful sample framework (Marshall, 1996) was constructed to enable sampling of patients with a range of gender, age, severity of arthritis, social class, length of disease and hospital.

Interviews

Data were collected using semi-structured qualitative interviews conducted by Memel with participants in their own homes. They lasted between 45 and 60 minutes and were audiotaped. Participants were told that the interviews were confidential and that the interviewer was an academic GP but that he did not know the identity of their GP or hospital specialist (except for the single rheumatologist at one hospital). They were also informed that the purpose was to explore both their experiences and views on the care for people with rheumatoid arthritis from GPs and hospital specialists. A topic guide was used to shape the interviews. (Figure 1) This was developed from a review of relevant literature together with responses given in informal discussions with colleagues and with patients not involved in the main study. However the exact questions addressed in each interview varied in accordance with the priorities of the interviewee. Moreover, in line with the grounded theory approach, (Strauss and Corbin, 1990) new questions were added as the

interview process progressed. The number of interviews was determined by the point at which it became apparent that additional interviews were not producing new themes. At the end of the interview participants completed a Health Assessment Questionnaire (HAQ) (Kirwan and Reeback, 1986) to assess their level of functional disability.

Analysis

The audiotaped interviews were transcribed and these transcripts together with field notes and reflective comments were used for further analysis. The analysis was informed by the principles of grounded theory. Essentially, this involved developing hypotheses from the 'grounded' transcribed data rather than defining them *a priori*. In other words it comprised an inductive process of coding phrases from the transcripts, placing all similarly coded phrases together (in categories) and then identifying overall themes. A description of each theme was drawn up, building on the coded data. Gradually an analytical account that encompassed all the coded data was assembled. Finally,

- **history of arthritis and its effects**
- **the care received from GPs and hospital specialists for arthritis**
- **the perceived differences between GP and hospital specialist care**
- **the perceived relationship between GPs and hospital specialists**
- **involvement with other health professionals**
- **ways in which arthritis care could be improved**
- **views on a shift to a shared care system under which patients with rheumatoid arthritis see their GP for routine care, but patients and GPs have rapid access to specialist services in times of need**

Figure 1 Topics covered in interview schedule.

a further search of the data was undertaken to verify or disconfirm the findings.

Phrases from the transcribed data were coded and categorized by Memel using the computer software programme ATLAS/ti (Muhr, 1997) which has been developed for the management of qualitative data. Three interviews were double coded by Somerset and showing no major inconsistencies. Memel and Somerset carried out the development of categories and the subsequent reduction into major themes jointly, by repeated reading and summarizing of the data. The researchers discussed any differences of opinion and a consensus was reached. The major themes reported here featured in all the interviews, and they incorporate categories that encompassed most of the data. Checks for credibility involved triangulation with the available written literature from medical and sociological sources, arthritis charities, and people with rheumatoid arthritis; observation in a rheumatology outpatient clinic (Memel); informal discussion with people with arthritis, GPs and rheumatologists; and the data from an ongoing study exploring the perceptions of care of patients with multiple sclerosis (Somerset *et al.*, 2001)

Results

Twelve people were interviewed and included people with a range of ages, social class, severity of disability, and length of disease as shown in Table 1. Within the overall topic of the experiences and views of care for rheumatoid arthritis, four major themes arose from the data (see Figure 2).

Doctors and their roles

Nearly all participants felt that there was a very strong role for the hospital specialist in their continuing care and this included regular review consultations. This was predominantly due to the specialized knowledge they were perceived to hold. As well as leading to good disease management, this was reassuring for participants. There were misgivings about a new shared care system being introduced under which patients see their GP for routine care. Participants that were prepared to consider this management for themselves added that they would require direct access to the hospital specialist at times of need. Participants varied in

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Table 1 Characteristics of participants

Gender	
Male	4
Female	8
Age	
30–49	2
50–59	2
60–69	6
70–79	2
Social class	
Manual	7
Non Manual	5
Severity (HAQ)	
Mild	3
Moderate	5
Severe	4
Length of disease (years)	
2–5	3
6–10	3
11–15	4
>15	2
Hospital	
A	8
B	4

the extent to which they felt that the primary health care team also had an active role in their disease management. Several felt this was limited to the GP issuing repeat prescriptions, and the practice nurse monitoring disease modifying drugs with blood and urine tests.

Because I'll be honest I would rather go once a year for two minutes to [the specialist] than I would go every so often to my GP. Unless I felt he knew more about rheumatoid arthritis and why should I and . . . I really shouldn't feel that way but he can't poor soul know everything about everything can he? In all fairness. (Participant 4)

Most participants felt equally able to talk to GP and hospital specialist about issues such as depression, and coping with the disease, and there was no overall perception that there was a stronger role for the GP in dealing with psychosocial issues. Nor was there a strong advocate role for the GP, either in explaining or expediting hospital care.

An important role for the GP was perceived to

<p>Doctors and their roles</p> <ul style="list-style-type: none"> • role of GP • role of hospital doctor • GP consultation • hospital doctor consultation • GP – hospital doctor relationship • doctor knowledge • accessibility • time with doctor • delay • diagnosis • referral • investigations 	<p>Doctor – patient relationship</p> <ul style="list-style-type: none"> • doctor-patient relationship – GP • doctor-patient relationship – hospital doctor • conflict with GP • conflict with hospital doctor • empathy • doctor knowledge • fault/blame • troubling doctors • patient assertion • doctor can/cannot do anything • length of relationship • particular doctor • gender issues
<p>Managing their illness</p> <ul style="list-style-type: none"> • coping with illness • future • uncertainty • other people with arthritis • information • self help • self knowledge • anxiety/worry/anger • feeling low 	<p>Social aspects</p> <ul style="list-style-type: none"> • welfare benefits • work • aids • family • friends • age

Figure 2 Major themes and categories analysed from the data.

be the initial referral of the participant to the rheumatologist. However, participants did not describe being involved in the referral decision, and several wished that they had been referred earlier. Participants were sometimes unclear why they had been referred to a specialist, whereas the GP had managed other diseases without specialist help, though others suggested this was due to the seriousness of the disease.

Some participants, particularly those who seemed to hold the most medical knowledge about RA, divided problems relating to their arthritis between those that they would take to the GP and those they would rather address to the rheumatologist. However, most people tried to cope with any new problems until their next hospital appoint-

ment, rather than consult their GP. This was often justified by relating previous experiences of consultations which either resulted in inaction, or in the GP subsequently seeking the advice of the specialist.

The easier accessibility both in terms of time and place of the GP compared to the specialist was regarded as an advantage. Participants could initiate consultations with GPs and usually choose which doctor they wished to see, whereas this was seldom possible with specialists.

I mean, it's easier at the end of the day to make an appointment to see the GP or to even pick up the phone and ask if it is possible to speak to him. Whereas if you do that

with the hospital there is a chance it could be either one of the consultant's days off or he is doing a ward round or you could just not speak to him, you would have to go through his secretary. They would then in turn nine times out of ten don't get back to you. But the GP it would be easier. (Participant 1).

However, a few participants were able to have more direct access with the specialist by telephone or by asking their secretary for an earlier appointment, and this facility was highly valued. Because of the easier accessibility of the GP, problems perceived as urgent were usually presented initially to the GP. The direct access available to GPs however made some participants anxious about 'troubling doctors' (Participant 10). Participants feared being regarded as neurotic or malingering, and often described consulting the doctor as a last resort, after discussion with family members.

The nature of the relationship between GP and hospital specialist was frequently unclear to participants, though they described it as good when they thought that the two doctors knew each other. The flow of information appeared to be in one direction—from specialist to GP, and participants described the frustration they experienced when their GP did not have the relevant information such as investigation results from the hospital. Generally the specialist was perceived to be in charge, rather than this being a relationship of equals.

I suppose it's like in the school we can't exactly tell the children what we want them to do and that because at the end of the day it goes down to the headmistress. I suppose with the GP he can't prescribe a completely different medication without the consultant's go ahead. (Participant 1).

Some participants thought there were rules limiting the extent to which GPs could prescribe arthritis medication, though others described persuading their GP to prescribe disease modifying medication because of the long wait to see a specialist. Several participants described feeling stuck in the middle between specialist and GP, and sometimes felt one doctor blamed them for, what they believed was, another doctor's fault.

Oh yes, on three different occasions [the specialist said], 'I can't understand why you

have let this go like this', and I didn't take any notice... and then the third time I thought well no, I thought why should you blame me when I've been seeing doctors in the past. (Participant 2)

The fragmentation of care emerged as a stronger issue if participants were seeing several specialists for different medical conditions. The GP was not described in this situation as having a co-ordinating role.

Doctor – patient relationship

Knowledge and empathy emerged as important factors when participants described the relationship between themselves and their doctors. It was in the field of knowledge that there were major differences between how they perceived specialists and GPs. However there was no sense that the specialists were just technical experts. It seemed equally important for their relationships with specialists and with GPs that participants felt they were listened to, taken seriously and understood. Those demonstrating good empathic relationships used phrases such as *'I talk to her like I talk to my sister'* (Participant 12). Participants often recounted critical incidents when there had been conflict during a consultation with a doctor. Sometimes this led to openness and great improvement in the doctor patient relationship, but in other cases it led to long-standing continuing dissatisfactions and distrust. Such critical incidents arose during both specialist and GP consultations; however with GPs in their role as family doctors, the incidents often concerned consultations with other family members.

Potent causes of conflict, particularly with GPs, were delays in making the initial diagnosis and in subsequent disease management, and being treated as anxious or depressed when the participant felt that there was a serious physical problem. Some participants described finding it difficult to assess their GPs level of knowledge about arthritis, but others felt this did not matter as the doctor patient relationship was all based on trust. Several participants commented on how difficult it was to be assertive with either GPs or specialists when feeling ill.

because I was at my lowest then I didn't sort of say: "you know I'm not messing about here", you know perhaps I should have sort

of said to him you know. Been a bit more sort of bold but you don't, you feel very susceptible when you are feeling low and ill you know, you don't take that sort of the upper hand whereas you normally perhaps would do. (Participant 11)

Most participants placed importance on seeing the same GP regarding their arthritis, yet were accepting that often they could not see the same doctor in outpatients. They described feeling that the specialist influenced the attitudes of the rest of his or her team of doctors. They also felt it was important that the GP knew them as a person, but opinions varied as to whether the specialist knew them, and the extent to which this was important.

I'm not gonna see them on a regular basis I am only dependent on them for this one particular thing and they are the experts and that is why I have to go there to see them. And so it's not really as personal a service as your GP because your GP is involved with your family with you alone and so I think it is important that they or you think of them as someone you can talk to about your background. (Participant 9).

Managing their illness

The ways that participants sought medical help often seemed to be associated with the manner in which they coped with the illness. One participant described great reluctance to seek medical help, which seemed to reflect a wish not to acknowledge the disease and its effects, whereas another very actively sought out information, describing how this gave her control over the disease. Participants vividly described the time of receiving the diagnosis, for some it was devastating '*I thought I would probably end up in a wheelchair*' (Participant 8) whereas for others it was a relief to know what was actually wrong, that they were not '*just getting really neurotic*' (Participant 11), or did not have another disease such as cancer or multiple sclerosis.

Some participants described feelings of great frustration or depression as they struggled to come to terms with the illness and its effects on work, family life and ambitions, and uncertainty about the future. Participants described being listened to equally by GPs and hospital doctors when express-

ing these feelings, and rarely described being given psychotropic medication.

Participants varied in their views as to the amount of control that they felt they had over the disease. Generally they felt that a positive mental attitude was important, but this varied from fighting the illness and not giving in to being sensible and knowing when to stop.

I mean I'm a very, if I want to do something whether it will hurt or not I'm determined that I will do it . . . I mean I went up there I went horse riding, I sort of pushed myself. I would sit on the horse and I would tell everybody, no I'm fine it doesn't hurt because I want to do it, I won't let it get the better of me but there again saying that there are days it does get the better of me I find that there's nothing I can do. (Participant 1)

They also varied in the degree to which they felt that doctors and medicine were able to control the disease, this was often associated with how disabled they had become. Participants described ambivalence about seeing people who were more severely affected than they were by arthritis. On the one hand the contrast reassured them that their disability was not as extensive, but on the other hand, they were reminded that it may progress in the future. They described receiving support from other people with arthritis when inpatients in hospital, but they had neither maintained these relationships nor joined self help groups.

Social aspects

When a disease like rheumatoid arthritis causes disability, the capacity for health and social care professionals to help often extends to social interventions such as the provision of functional and financial help. Nearly all the participants had aids for daily living, but there was no consistent way in which they had gained relevant information or acquired the aids.

Well again it belonged to her uncle... and err when he died, that was his helping hand. So I got it and I err keep it down one of my chair down by the side of the settee just down there, so I can pick things like that all right. (Participant 5)

The exceptions were those participants who had had inpatient treatment for their rheumatoid

arthritis, during which time they were assessed by physiotherapists, occupational therapists and social workers. Participants were often unsure whether to turn to the hospital or the GP's surgery for future help regarding aids and adaptations, or indeed whether this was part of their medical care.

Similarly participants often described finding out about disability welfare benefits such as attendance allowance in random ways, such as in discussion with friends, rather than from a health or social care professional. Although aware of posters and leaflets at both GP surgeries and hospital outpatient departments relating to these issues, the relevance to them personally had not been appreciated. Even a participant who had trained as a nurse, and was currently having difficulty coping at home following an ankle operation, was uncertain about where to go for help, and like most participants was depending on family and friends.

Discussion

This study has shown that patients with rheumatoid arthritis value highly the regular input they receive from specialist rheumatologists, not only because of their expert knowledge but also because they are able to talk to them about all aspects of their illness. Although GP services were perceived to be more accessible, people did not prefer to talk to their GP about psychosocial aspects of their illness and often they felt that their GPs did not have sufficient knowledge about disease management. The results of this study challenge, from patients' perspectives, views of the central role of the GP in the management of chronic illness, such as that GPs are the experts on psychological and social aspects of care (McWhinney, 1989). Furthermore, the results suggest that patients with rheumatoid arthritis would not welcome their care being shifted from secondary to primary care, without easy access to rheumatologists.

Several limitations need to be recognised with this study. Qualitative research seeks to uncover people's beliefs and understandings, it does not tell us how many people hold these views. Sampling is not designed to identify a group that is representative of a specific population. Rather it is intended to identify people who hold a range of pertinent characteristics. The findings from such a study are likely to have relevance to others who conform to

these characteristics (Murphy *et al.*, 1998, p 94–5). However, people who were in receipt of care from their GP alone were not included in this study and therefore it would be inappropriate to generalize these findings to that group. It has been estimated that in the South West of England 30% of patients with rheumatoid arthritis are under the regular care of rheumatologists (Kirwan and Snow, 1991), but they are likely to be the more disabled patients and those on complex medication.

Participants were contrasting the present hospital specialist doctor and GP care commonly provided in the United Kingdom, rather than any new structured form of shared care, and it is well known that patients prefer what they are accustomed to in terms of service style. However, other models of shared care are also used or about to be implemented and it would be useful to investigate satisfaction with these by interviewing patients before and after their introduction. For instance, participants in this study made little mention of the role of nurses. This omission may reflect local service provision, as nationwide there is increasing involvement of nurses both in primary and secondary care.

What are the implications of this for the future provision of care for patients with rheumatoid arthritis? First, it would appear that any move to encourage patients to seek more care from their GP would have to be accompanied by a system of easy access to specialists, by GPs and patients. Direct access to specialists plus clear guidelines as to the GP and specialists roles, may allay many patients' misgivings (Hewlett *et al.*, 2000). Secondly, there are social aspects of care such as aids for daily living and welfare benefits, that are currently inadequately met in either general practice or hospital, and better systems need to be developed involving other health and social care professionals.

Thirdly, patients clearly have concerns regarding GP knowledge about the management of rheumatoid arthritis. Increased educational input to GPs about rheumatology, as advocated by the Primary Care Rheumatology Society (Primary Care Rheumatology Society, 1996) would help. However, primary care is currently adopting a greater role in the management of a large range of chronic diseases, each of which require greater knowledge. In the UK despite the recent advocacy in the NHS plan of the development of GP specialists (NHS

Plan, 2000), GPs have generally not chosen to specialize within partnerships on the care of different chronic diseases (Greenhalgh, 1994). The development of primary care based specialist nurses, shared between practices in a locality, as has recently been advocated for epilepsy (Mills *et al.*, 1997), and the introduction of structured care as has happened for asthma and diabetes (Greenhalgh, 1994) may represent ways forward.

In conclusion, this study has shown that this group of people with rheumatoid arthritis currently prefer to have regular contact with a rheumatologist rather than obtaining care for their arthritis mainly from their GP. It is important to incorporate users' views with current moves to shift the balance of care to primary care, and to ensure that the overall quality of care is not diminished. Moreover, there may be factors in the high quality of care provided to patients with rheumatoid arthritis that can be applied to the care of other chronic illnesses.

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