Factors influencing the beliefs of patients with rheumatoid arthritis regarding disease-modifying medication

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Objective. To investigate factors influencing the beliefs of patients with rheumatoid arthritis (RA) regarding disease-modifying medication.

Method. Twenty-nine patients with RA either starting a disease-modifying anti-rheumatic drug (DMARD) for the first time or changing DMARD were recruited. Semi-structured interviews, activity diaries and focus groups were conducted over 9 months. A coding framework was developed and data analysed using the constant comparative method to identify key themes.

Results. DMARDs were perceived as central to the management of RA but strong concerns were expressed about potential long-term effects. Beliefs about DMARDs were informed by material from a wide range of sources. Judgements of efficacy were influenced by symptom relief, occurrence of side-effects and perception of alternative treatment options. Perception, reporting and tolerance of side-effects differed widely between individuals. The emotional impact of starting and being withdrawn from medication appeared stronger in people with more experience of DMARD use.

Conclusions. Patients have complex and evolving belief systems relating to DMARDs. Understanding these systems will facilitate the provision of appropriate information and effective support not only in decision-making about treatment but also in relation to discontinuing treatment.

Key words: Beliefs, Decision-making, Medication, Rheumatoid arthritis.

The aim of involving patients more fully in decisions about their healthcare is reflected in health policy [1, 2] and by an increasing literature addressing issues such as shared decision-making [3–6], communicating risk [7–9] and the development of clinical tools to facilitate the involvement of patients in treatment decisions [10, 11]. Developing a better understanding of patients’ preferences for treatment has obvious potential to inform interventions designed to enhance adherence and improve health outcomes [7] and requires an understanding of the factors that influence patients’ beliefs and decisions.

Studies exploring patients’ beliefs about disease-modifying anti-rheumatic drugs (DMARDs) have revealed anxieties about using what are perceived as powerful and toxic medications [12, 13]. A number of studies have focused primarily on identifying reasons for non-adherence or on evaluating the efficacy of interventions to enhance adherence [14–19] rather than understanding the rationale for decision-making. Recent work [13, 20, 21] has challenged conventional concepts of non-adherence by suggesting that such behaviour may be the consequence of a rational decision-making process conducted by patients. Whilst social cognition models such as the Health Beliefs Model [22] and the Theory of Planned Behaviour [23] seek to understand patients’ treatment decisions by focusing on the beliefs they hold about their illness, it has been suggested that a more appropriate model would also incorporate beliefs about treatment [24].

This study sought to investigate the factors influencing patients’ beliefs about DMARDs and the influence these have on medication-related decisions.

Methods

A qualitative methodology, comprising in-depth interviews, activity diaries and focus groups was used. Purposive sampling was used to recruit 29 participants, 13 were commencing a DMARD for the first time and 16 had experience of using several DMARDs. Data were collected over 9 months to provide insights into processes of change, factors influencing medication-related decisions and judgements of efficacy. The sample provided heterogeneity in terms of age, gender and social situation, together with sufficient depth of qualitative data whilst being manageable in relation to project resources. Participants were recruited from departments of rheumatology in three hospitals. Ethical approval was obtained and written consent gained from all participants.

In-depth interviews, which aim to find out what others think and know as expressed in their own words [25], were used to obtain data on the person’s experience of rheumatoid arthritis (RA), its treatment and its impact on lifestyle and functional ability. All interviews were conducted by LG and guided by a schedule. The initial schedule was informed by a review of literature relating to beliefs about medication and functional change in RA, and by discussions with colleagues and patients. As the research progressed the schedule was adapted to reflect insights gained from participants, consistent with the iterative nature of qualitative inquiry.

After the first interview patients completed a 7-day activity diary and underwent an interview focusing upon changes in daily activities. These provided a first-hand account of experiences to
which researchers did not have direct access [26]. A second diary and interview were completed after 3 months. All interviews took place in patients’ homes and lasted between 1 and 2 h.

At the end of the fieldwork participants attended two focus groups designed to explore perceptions and opinions on the defined area of interest [27]. Discussion examined key issues identified during analysis. Triangulation of these methods provided different perspectives of participants’ experiences, enhanced the richness and depth of data and increased the validity of the data by demonstrating that the same conclusions could be drawn when different methods were used to observe the same phenomena [28]. Interviews and focus groups were taped and transcribed. Data were transferred into ATLASi for analysis. All transcripts were read and coded using the constant comparative method, comprising open, axial and selective coding, consistent with a grounded theory approach [29].

Results

Participants

Twenty-nine patients agreed to participate (Table 1).

Beliefs about DMARDs

Of the 29 participants 24 had not taken medication on a long-term basis prior to the onset of their RA. Long-term medication use was described negatively and associated with ‘reliance’ and ‘dependence’. All participants expressed the view that medication use in general should be minimized and many tried to restrict medication intake, e.g. by taking minimal analgesia.

Participants believed there was no choice about whether or not to take DMARDs as they were necessary to preserve joint structures, reduce pain and increase quality of life. However, DMARDs were perceived to be ‘powerful’, ‘strong’ and ‘toxic’ with implications for long-term use.

I left more upset not because of what had been diagnosed but because of what he had said [about medication use]. All I could say to my husband was, ‘I don’t want this, I don’t want to be stuck on medication for the rest of my life. What is it going to do, you don’t know what it is doing to the rest of you, I don’t want to do it’. . . . I thought, yes, if it does slow down the process, great but then I’m meant to take them from here on in forever, cause if ever I come off it will immediately come back and I’m just really nervous about that. [Mrs M]

If I had my way I’d take none of them, it’s all toxic no matter how good or how much it helps there’s always a price for it, I haven’t got the choice but if I had my way, if I thought I could get through it I would. [Mr P]

Two patients associated the risk of DMARD use with reduced life expectancy:

. . . the issue I decided to take the drug on was quality of life;’ cause all these drugs shorten your life end of story, so the question is do you want to be old and crippled or do you want to die younger. [Mrs A]

Side-effects

Different attitudes were expressed towards potential side-effects:

. . . you know 10-to-1 they may not happen. You can’t just not take medication because of what you think might happen, you’ve just got to give it a go and see what does actually happen. [Mrs A]

I could be one of the 35 percent where there is a remission in the disease where it stops being active, or is only active to the extent that it’s a minor irritation and here I ambuggering up me system by taking all these drugs. It’s not that straightforward psychologically. [Mrs V]

Side-effects were perceived by some as a natural process of the body’s adjustment to ‘powerful’ medication which in some cases led to discomfort being unreported and tolerated for weeks:

I didn’t ring up straight away because I thought well they’re quite toxic and if my blood results, [pause] I really thought that the side-effects [tinnitus] were a nuisance whereas I was quite confident that if my blood results hadn’t been right they would have let me know straight away and that’s what I would have been really concerned about. I think it’s perfectly natural to have some sort of reaction to quite toxic drugs. [Mrs F]

The number of side effects outlined in written information was described as ‘scary’ and ‘confusing’ and variation was noted in peoples’ ability to detect and willingness to report side-effects not identified by routine monitoring. People using DMARDs for the first time had more difficulty identifying such side-effects and were also more reluctant to contact clinic staff between appointments to ask for advice. People with more experience of DMARDs perceived the challenge to be that of obtaining a balance between controlling symptoms whilst minimizing side-effects:

. . . when you take toxic drugs it’s a toss up isn’t it really between how the drug makes you feel and how the illness you’ve got makes you feel. [Mr I]

If the medication was perceived as beneficial, or the number of alternatives perceived as limited, people were more prepared to tolerate and in some instances not report side-effects such as nausea, diarrhoea and feeling generally unwell:

I’ll put up with all the side-effects as long as I have to, I want to be able to move, I want to be able to live a normal life so I will put up with them, they are better than they were but I’ve lost well over a stone. [Mr D]

However, when medication was not perceived as beneficial concerns about side-effects were voiced more frequently and the rationale for continued use was questioned.

Beliefs about efficacy

Efficacy was judged by reduction in symptoms, prevention of deterioration and increased quality of life. Differences were
identified in the expectations of those starting a DMARD for the first time compared with those with more experience of DMARD use, the former having more confidence that the medication could control symptoms, prevent joint damage (often equated with preventing deformities) and maintain improvement, the latter being more guarded in their assessment of efficacy with judgements being made over a longer period of time and a tendency to expect symptoms to be reduced but not alleviated.

The belief that DMARDs were meant to prevent further deterioration and uncertainty about how a person would feel if they were not taking the medication were reasons cited for continuing medication when it was not perceived to be improving disease status:

It’s meant to stop things getting worse isn’t it. I don’t suppose it’s meant to make things better and I don’t feel like it does do, I mean it might be, I might be worse without, I don’t know now whether it is working or it’s just that I’m not getting worse. [Mrs D]

**Sources of information**

In each hospital the primary sources of information were the rheumatologist and clinical nurse specialist. Twenty-one patients also referred to newspapers, magazines, self-help group newsletters, the internet and television. Some patients had found this information themselves, whilst for others it had been provided by family and friends. Such information related to specific prescribed medication as well as to other medications such as biological therapies. People with longstanding RA also cited other patients as a source of medication-related information.

**Being withdrawn from treatment**

Sixteen people had experience of DMARDs ‘not working’. This was rationalized in different ways, e.g. medication having a time-limited effect, the body ‘building up tolerance’ to medication, and a process of ‘trial and error’. Being withdrawn from a DMARD was associated with increased anxiety, especially if the medication was perceived as beneficial:

You’re so frightened when you come off them because you feel so well and then you know when you come off that within a few weeks . . . you’ll be back to square one and you won’t be able to do anything and it is it’s frightening. [Mrs J]

Some people felt that healthcare professionals did not appreciate the psychological impact of being withdrawn from medication:

I still don’t think they realise just the impact, the psychological and emotional impact of when it doesn’t work out. [Mrs V]

Another concern expressed commonly was the possibility of running out of treatment options, associated with an increasing desire to understand why medications were not working.

**Discussion**

This study highlights the multidimensional, dynamic nature of patients’ beliefs about DMARDs. These are formed by beliefs about both efficacy and side-effects, together with evolving experience. A consistent tension was identified by participants: DMARDs were perceived as central to the management of RA but strong concerns were expressed about potential long-term effects, so whilst the desire to minimize medication was expressed consistently the use of DMARDs was perceived as essential. This is consistent with previous work suggesting that patients’ beliefs about medication comprise general beliefs about medication as well as beliefs about specific treatments [24]. Our results suggest that this tension may impact upon use of other medication as patients try to minimize their overall medication intake. This highlights an area that needs to be further addressed and may have implications for patients with co-morbid conditions.

Whilst symptom experience plays a key role in judging treatment efficacy [30, 31] our data suggest that such judgements are more complex in RA since prevention of deterioration may be accepted as a secondary outcome if the primary outcome of symptom relief is not achieved. These findings are consistent with those of Lorish et al. [14] who found that fear of the condition worsening was one of the reasons cited for taking what were perceived to be ineffective medications. As suggested in previous studies [31, 32] a ‘cost–benefit analysis’ was undertaken with concerns about possible adverse effects and the perceived power and toxicity of DMARDs being weighed against symptom control, preventing deterioration and maintaining quality of life. However, beliefs about the availability of other treatment options also appeared to influence decisions, e.g. willingness to tolerate side-effects. These data were collected at a time when biological therapies were not yet widely used and before their possible impact on decisions relating to DMARDs could be explored.

Our data also show that patients’ beliefs about side-effects influence their detection, tolerance and reporting of these events. Such beliefs were not only linked to experience but appeared to be informed by different attitudes to risk, as found by Fraenkel et al. [12]. Recent studies have found that patients can experience difficulty with concepts of risk assessment [8, 9]; however, our data suggest that patients are able to describe the risks they associate with DMARDs and the rationale for their decisions. The need to develop tools that are meaningful to patients and informed by an understanding of how they understand risk and benefit has been highlighted [11] and is particularly important in RA where there are often different treatment options, therapies have distinct risk profiles and many interventions require regular long-term monitoring with consequences in terms of incorporating monitoring activities into lifestyles [12]. The finding that some patients may control the disclosure of information within consultations in relation to over- and under-reporting of side-effects in order to obtain a preferred outcome is as yet unexplored, but has important implications for work aimed at identifying responsiveness to new biological therapies and in the interpretation and application of pharmacogenetic data.

In common with other studies [31, 33, 34] we found that patients wanted to be informed fully about their medication and used a range of information to inform their beliefs and decisions. Research on shared decision-making and communication about medication has tended to focus on doctor–patient communication, but, whilst this yields much information, it focuses on only one aspect of the social context in which beliefs are formed and decisions made [35]. Much attention has focused on developing effective information for patients commencing medication, but less on the impact of medication being withdrawn and the influence of adverse events on future decisions. Our data suggest that being withdrawn from medication has an associated psychological impact in terms of increased anxiety, decreased expectations, concerns about running out of treatment options and seeking explanations as to why medication is not working. The evolving nature of patients’ experience influenced the kind of information they sought to rationalize such experiences and to make future decisions. Therefore, discussions and information should be set within this context. As suggested by Donovan [21], patients are not ‘blank sheets’ awaiting instructions but hold their own beliefs and theories about their illness and its treatment.

Developing a theoretical basis for patient decision-making requires further exploration of these issues and their relationships. Understanding the beliefs that patients possess will enable advice...
to be tailored to the individual and appropriate support to be given, not only at commencement of treatment but also when treatment is withdrawn. Patients should be actively encouraged to discuss their beliefs and concerns relating to treatment as such beliefs have the ability to influence adherence, judgement of efficacy, willingness to tolerate side-effects and future medication-related decisions.

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### References