

Patient Satisfaction with Rheumatology Practitioner Clinics: Can We Achieve Concordance by Meeting Patients' Information Needs and Encouraging Participatory Decision Making?

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Abstract

Introduction: The objective of this study was to determine if patient information needs are being met and the level of patient satisfaction with rheumatology practitioners in participatory decision-making and thereby indirectly explore whether concordance was achieved. **Materials and Methods:** The design was a cross-sectional postal questionnaire survey of 420 patients attending outpatient clinics at the Norfolk and Norwich University Hospital who were taking disease modifying anti-rheumatic drugs (DMARDs) or a biological treatment. The population served is ethnically homogeneous and predominantly Caucasian. **Results:** The response rate was 76%. Most respondents (79%) had inflammatory arthritis while 66% had rheumatoid arthritis. Seventy-seven per cent of patients reported that the rationale behind commencing treatment was explained and that they were given ample opportunities to ask questions. Eighty-two per cent said they were given an appropriate amount of information. Sixty-four per cent of patients were satisfied with their level of participation in the decision-making process, although a substantial number (25%) said that information from different sources was conflicting. There was no correlation between concern about side effects and patients' perceptions of the effectiveness of medication. Females were more concerned than males about possible side effects; $P=0.009$, using the Mann-Whitney U test. One third of the patients altered their medication in response to whether their arthritis felt better or worse. **Conclusion:** The majority of patients were satisfied that their information needs were met and with the care provided in the practitioner clinic. Participatory decision-making was sub-optimal despite patient satisfaction with the amount of time allocated to meeting their information needs. We found that patients exercise autonomy in managing their arthritis by regulating their medications through an active decision-making process, which is informed by their previous experience of medication, and how well controlled they felt their arthritis was. Research into this decision-making process may hold the key to achieving concordance.

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Introduction

The evidence suggests that many patients do not take their medications as prescribed. Two studies estimate that as many as 50% of patients, particularly those with chronic conditions do not adhere to their medications.^{1,2} This has considerable implications for health service costs and patient care. In the past, the terms "compliance" or "adherence" were used to signify the theoretical intention of prescription. "Concordance" describes the process whereby the patient and healthcare professional reach an

agreement on how a drug will be used.³ The implication is that the healthcare professional gains a better understanding of the patient's perceptions of the illness/treatment while the patient is made aware of the consequences of adhering or not to treatment. It denotes a partnership between equals – patient and prescriber. The prescriber's role is obligatory with a duty to know and present contemporary scientific evidence and to elicit the patient's understanding and personal experience of their illness, which have been shaped by their social circumstances, behaviour and

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preferences.

The treatment of rheumatic conditions requires a multidisciplinary approach. Patient education is an integral part of the successful management of rheumatic diseases⁴ and can bring about improvements in health status.⁵⁻⁷ At the Norfolk and Norwich University Hospital, it is standard practice for all new patients being initiated on a disease modifying anti-rheumatic drug (DMARD) or biological treatment to have an appointment with a practitioner for counselling and education. All patients are provided written information in the form of an Arthritis Research Campaign medication leaflet to read prior to their appointment with the rheumatology practitioner. The need for treatment with a specified drug is discussed along with the potential benefits, side effects and monitoring arrangements. Patients' preferences and concerns are addressed and decision-making is shared. The rheumatology practitioner; a nurse specialist, occupational therapist or physiotherapist who has been trained to run these practitioner clinics continues regular monitoring in the hospital setting where medications and blood results are reviewed in between visits to the rheumatologist.

The patients' perspective on quality of care has often been conceptualised as patient satisfaction.^{8,9} Research is emerging into how to make healthcare more responsive to patients' needs by looking at healthcare aspects of inadequate quality in patients with rheumatoid arthritis.¹⁰ The aims of our study were to determine if patient information needs are being met, the impact of patient education on drug adherence and the level of patient satisfaction with rheumatology practitioners in participatory decision-making, thereby indirectly gauging whether concordance was achieved.

Materials and Methods

Four hundred and twenty sequential patients taking DMARDs or biological agents were recruited from outpatient clinics during a 2-week period and a set of questionnaires were mailed to them. Freepost envelopes were provided for return of the anonymous questionnaires. Patient demographics (age, sex, gender) were recorded.

Diagnosis and Medications

Patients were asked about their diagnosis and when the diagnosis was made. They had to select from a list of medications comprising DMARDs and biological agents they were currently taking and indicate the duration of treatment.

Patient Involvement in the Decision-Making Process

In order to assess patient involvement in the decision-making process, questions were asked which addressed the

adequacy of consultation time, the rationale behind starting treatment, whether opportunities were provided to ask questions, whether answers were comprehensible, whether there was active listening on the part of the practitioner, whether patient views were taken into consideration and if patients were as involved as they wished to be in the decision-making process about their medication. Respondents indicated their degree of agreement with each statement on a 3-point Likert scale, ranging from "yes, definitely" to "yes, to some extent" to "no".

Information About Medication

Patients were asked whether the purpose and potential side effects of the medication had been satisfactorily explained and whether the written and verbal information given was adequate and appropriate. Other sources of information used by patients in order to gain knowledge about their medication were detailed. They were also asked whether they had experienced any conflicting information about their medication and to what extent.

Patient Experience of Managing Medication

Data on compliance with treatment was collected. This included information on how and why patients altered their medication, to what extent they made changes to the amount and frequency of taking medication and whether they ever forgot to take their medication. Patients were invited to comment in their own words in response to the questions "If you have changed the amount or how often you take your medicines, what prompted you to do this?" and "If you forget to take your medicines what do you do then?" Respondents were asked to elaborate on any side effects they had experienced and if advice given to counteract these by the practitioner had been satisfactory. A 10-cm visual analogue scale (VAS) was used to capture patients' level of concern about possible side effects. Patients charted the extent to which they felt the medication was helping their disease on a second 10-cm VAS.

Data Analysis

Questionnaires were collated using MS Access. All statistical analysis was carried out using SPSS 11 for windows. Data distributions were not normal and therefore non-parametric analysis was conducted.

Results

Three hundred and nineteen (76%) of 420 patients replied, 206 of whom were female, 113 were male. Seventy-nine per cent of the respondents had inflammatory arthritis (66% rheumatoid arthritis). Two hundred and forty-six patients (76%) were receiving monotherapy (69% methotrexate). Nine per cent were on biological therapies (Fig. 1). The median duration of treatment was 3 years with

an IQR of 1.5 to 7 years. A third of patients had been diagnosed within the past 5 years indicating a substantial number of patients with early disease. The median disease duration was 9 years with an IQR of 4 to 17 years.

Seventy-one per cent considered that they had been given adequate time to discuss their condition while 25% reported that the discussion was limited. Seventy-seven per cent were satisfied that the health professional had explained the reasons for commencing the medication and had given them ample opportunity to ask questions. Ninety-one per cent were satisfied with the answers. Eighty-one per cent said that the health professional had listened to the patient's views. Sixty-four per cent said that they were involved as much as they wished to be in the decision-making process regarding medication, which included the factors as outlined above. Thirty per cent reported that they were not wholly involved in this process despite 99% of patients saying they were given the opportunity to ask questions. Seventy per cent said that the purpose of the medications was explained in a comprehensible manner. The majority of patients (89%) said that they had been advised as to the possible side effects of their medications but one third of the cohort would have preferred more information. Only 59% said that they had received the drug information literature, which is routinely given to each patient.

Eighty-two per cent said they were given an appropriate amount of information while 3% denied receiving any information at all. Twenty-five per cent reported experiencing conflicting information about medication from the various sources they used while 69% never or rarely had conflicting information. The various sources of information that were accessed included the general practice nurse (43%), general practitioner (37%), the internet (19%), magazines (17%), friends (10%) and patient support groups (3%).

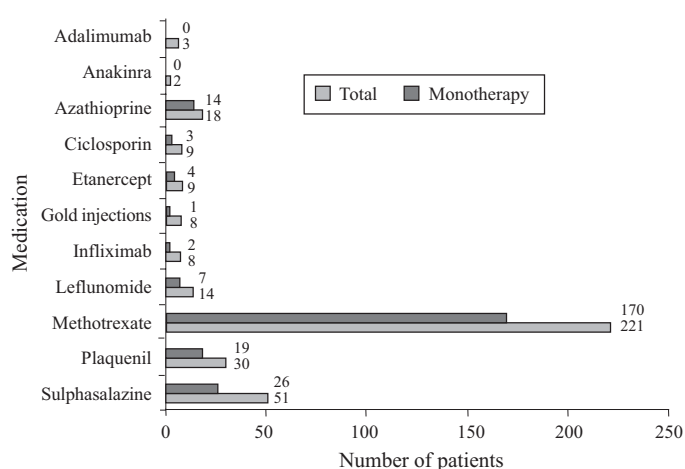


Fig. 1. Patient medication.

Thirty-four per cent of patients altered their medication (including steroids, DMARDs, anti-inflammatory drugs and analgesics) dosage and frequency at some time. Sixty-four per cent denied ever making any changes to their medications. The most common reason given for patients to alter their medication independent of medical advice was whether their arthritis felt better or worse (36%). Nineteen per cent altered their medication because of concern regarding side effects (Fig. 2).

Fifty-two per cent admitted to forgetting to take their medication on occasion. For daily dose treatment, patients reported that they omitted the dose and then took the next one as normal. For weekly medication, the patient took the weekly dose a day late and then continued taking the medication on that particular day of the week.

Fifty-three per cent reported adverse effects from their medication. Forty-five per cent said they received advice or treatment when they reported these but 4% were dissatisfied with the advice or treatment given. Females had a significantly higher level of concern about possible side effects (median, 57 mm; IQR, 36 to 85 mm) than males (median, 51 mm; IQR, 15 to 77 mm); $P = 0.009$, Mann-Whitney U test. Patients rated their concerns about side effects and the extent to which they felt that their medication was helping to relieve their disease on two 100-mm visual analogue scales. These 2 measures were then plotted into a scatter plot with the x-axis as the effectiveness of medication and the y-axis as the side effects concern (Fig. 3). Pearson's "r" correlation test on these 2 variables was not found to be statistically significant ($r = 0.126$, $n = 299$, $P = 0.029$, two-tailed).

Discussion

Rheumatology practitioner clinics aim to improve the

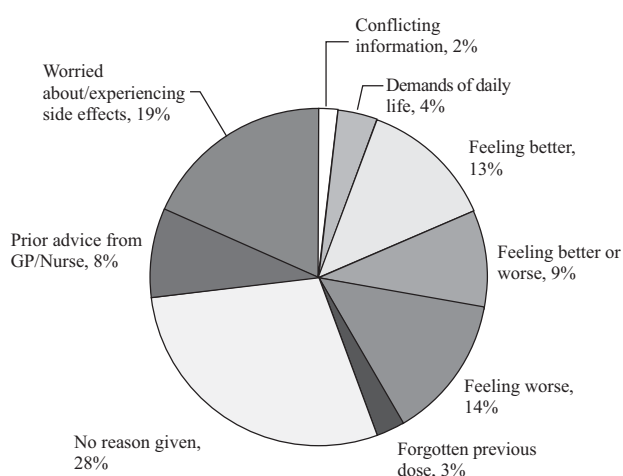


Fig. 2. Reasons for altering medication.

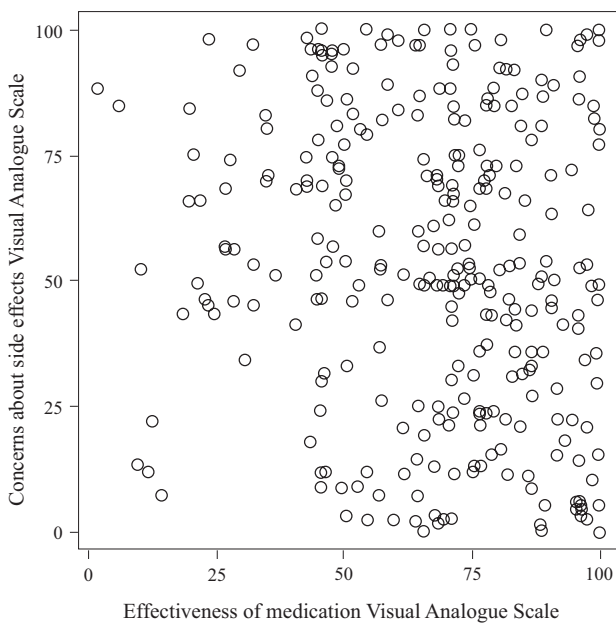


Fig. 3. Scatterplot of patients' ratings on 100-mm visual analogue scales of their level of concerns about side effects and their assessment of the effectiveness of the medication.

care of patients who are on potentially toxic therapies, which require long-term monitoring. In order to improve patients' understanding of their condition and to maximise the potential benefit of DMARD treatment, all new patients being initiated on treatment see a practitioner who elicits their views and discusses the pros and cons of medication, thereby involving the patient in the treatment decision.¹¹ In this setting, continuity of care is maintained through the development of a personal relationship with a patient and one journeys with the patient as their experience with their disease evolves. Being "patient-centred" acknowledges that patients pursue multiple interests which may be in tension with one another, thus information is tailored to each individual's needs, taking into account their beliefs and lifestyles.

Despite improvements in written information in the form of printed leaflets which improve patients' satisfaction and knowledge,¹² there is little effect on compliance.¹³ Leaflets tend to emphasise side effects while scarcely mentioning the expected benefits of use.

Patients' beliefs and attitudes influence how they take drugs.¹⁴ Many patients with chronic illnesses are ambivalent and experiment with dose titration and drug-free intervals.¹⁵ Their assessment of risk is primarily determined by emotions rather than facts¹⁶ as they extract the gist of the information provided to them and not the detail.¹⁷ Health professionals may facilitate patients' acceptance of treatment risk by clarifying the consequences of adverse effects to alleviate fear of the unknown. Eighty-nine per cent of our patients reported that they were informed about the possible side effects of medications whereas only two thirds said this

information was sufficient. The most common single reason the patients gave for making changes to their medication independently of medical advice was if they were experiencing side effects. Thirty-six per cent of our patients altered their medication frequency and dosage by either increasing it or decreasing it in response to whether their arthritis was bad or good. Traditionally, this would be conceptualized as non-adherence but may reflect active decision-making;¹⁵ it would not be seen as non-concordance provided patient-professional communication is maintained. Seventy-five per cent of our patients were satisfied with the time allocated to discuss their condition and the need for medications. Although 99% of our patients said they were given the opportunity to ask questions, 30% felt that they were not wholly involved in decision-making regarding their treatment, possibly because patients were referred for counselling regarding a particular drug and the patient was undecided about commencing treatment. A patient's decision about their level of involvement is important to the concordance process.¹⁸

The quality of the interaction between the health professional and the patient has a major influence on health outcomes.¹⁹ Patient willingness to risk adverse effects depends not only on the specific adverse effects, the expected benefits of a medication and previous experience with side-effects but also on the health professional-patient relationship. If patients are satisfied that health professionals are acting in their best interests, they are more likely to adhere to the medication regime.^{20,21} The practitioner who displays competence, a caring approach and a willingness to discuss the patient's expectations and fears creates an environment for decision-making based on trust. Patient are therefore more likely to ask questions and discuss risks fully, be better informed and be enabled to take an active role in the management of their arthritis.

Barlow et al²² found that psychological well being and disease acceptance are independent of disease duration. Many people with arthritis lack confidence in their ability to self-care and have low self-esteem. An important part of the rheumatology practitioner's role is dealing with these psychological problems.²³

Although non-compliance tends to increase with long-term medication regimens where the aim is preventive,²⁴ Lorish et al²⁵ found that fear of the condition worsening was a reason for taking what was perceived to be ineffective medications. Although we did not find any correlation between concern about side effects and patients' perceptions of the effectiveness of medication, which translated into poorer medication adherence, women were more concerned than men about possible side effects. Half of our patients said they occasionally forgot to take their medication. "Forgetfulness" in some cases represents the non-explicit denial of disease and its social consequences.²⁶

Comparisons of physician and patient values have consistently shown that these 2 populations differ with respect to what they judge to be important.²⁷

Identification of patients' preferences for important health and symptom status outcomes (for example, issues like pain, activities involving working at a job or playing sports) may help to direct therapeutic intervention, thereby leading to increased satisfaction and compliance. The rheumatology practitioner often acts as a link between the patient and the rheumatologist by highlighting these aspects.

Two studies have found that patients with high arthritis disease activity were more compliant with treatment advice than those with low disease activity.^{28,29} In this study, patients were not asked to report their health status but one third of our cohort who altered their medication dosage and frequency said they increased their medication if their arthritis was bad and decreased it if they were feeling better.

Conclusion

While patients were satisfied with the care provided in the practitioner clinic, conflicting information regarding medications may result in increased concern about side effects and poorer medication adherence. Although patients were more likely to comply with a treatment decision with which they were involved and fully agree with, i.e. are in concordance with, this cannot be assumed. Although we did not achieve concordance in our rheumatology practitioner clinics, nevertheless this approach to medication prescribing is in line with the move in the National Health Service away from the paternalistic approach to medication compliance towards integration of patients in the management of their chronic disease.

Patients strive for autonomy in living with their chronic disease. By meeting their information needs and participatory decision-making in the rheumatology practitioner clinics, we aim to empower them in the management of their disease and in so doing, improve health outcomes.

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