Editorial

‘Compliance’ is futile but is ‘concordance’ between rheumatology patients and health professionals attainable?

The extent to which patients take prescribed medications ‘as directed’ and why they do not have been important issues in health research for many decades [1] and subject to recent review [2–6]. These issues are important in rheumatic diseases, given the primary reliance upon medication to control symptoms and improve patients’ functional ability and longevity [7]. Not taking required medications can therefore have both a personal health impact and health-economics consequences [3]. In recent years patients have shown increased interest in their health-care; this is partially due to a boom in access to information technology coupled with increased health coverage in traditional media sources [8]. A fresh approach to medication prescribing is required, one that evolves away from the paternalistic approach of patient compliance or adherence towards the more recently introduced philosophy of patient–professional concordance.

Previous research has lacked consistent definition and measurement of medication-taking and, particularly in rheumatology, has rarely investigated biopsychosocial predictors in a longitudinal or interventional fashion. In this editorial we reiterate the definitions of patient ‘compliance’ and ‘adherence’ and comment on the implications of using these terms. We review some of the relevant research findings on patient compliance/adherence in rheumatology and finish by outlining the more recent philosophical and clinical move towards patient–professional concordance along with some of the practical implications for its impending application in routine clinical practice. We highlight potential predictors of medication taking that should be integrated in future research. We also examine how medication taking and its potential predictors should be measured in research by detailing key methods and identifying areas in which they can be applied. Definitions of key concepts and our recommended measures of these are summarized in Table 1.

The conceptualization and operationalization of the ‘correct’ taking of prescription medications often reflects the dominant paternalistic approach to health-care. As Charavel et al. [9] put it, ‘the physician–patient relationship has always implied that the physician alone makes the treatment decision, while the passive and dependent patient is obliged to comply with the physician’s prescription.’ (p. 93, emphasis added.)

The verb ‘comply’ implies enforcement through its association with ‘bending the will of another’ ([10], etymology section). This has led to increased use of the verb ‘adhere’, which literally means ‘to stick to’ ([11], etymology section), to describe medication-taking. ‘Adherence’ is described as ‘persistence in a practice or tenet; steady observance or maintenance.’ ([12], section 3). This definition captures the routine that people with chronic rheumatic disease ideally engage in when taking prescription medication.

The classic estimate of adherence is that only around 50% of patients adhere to prescription medications [1]. Ten days after a new prescription has been filled, 30% of patients with chronic diseases have missed at least one dose of the medication not on medical advice, half of them unintentionally, the others intentionally [13]. Reasons for missing a dose include side-effects, concerns about the medication and an expressed need for further information about the disease or medication itself, particularly among intentionally non-adherent patients.

Medication compliance/adherence may be operationalized (i.e. conceptualized and measured) in many different ways [5], including multi-item questionnaire scales, individual ordinal/categorical questionnaire items, patients’ and physicians’ categorizations and independent observations such as prescription refill monitoring, electronic dispenser monitoring or metabolite/tracer measuring. We will now describe how estimates of adherence may differ depending on the ways in which adherence is assessed, as well as the exact disease and medication investigated. We also provide details of example studies that raise some of the central issues requiring attention in this field.

In general rheumatology clinics, Berry et al. [14] found global non-adherence (answering ‘no’ to the question ‘Have you taken medicine regularly as prescribed or directed?’) more common among new (28%) than follow-up patients (1%). No new patients were on disease-modifying anti-rheumatic drugs (DMARDs), but they were more likely than follow-up patients to be on NSAIDs. As NSAIDs are suitable for use according to symptoms, up to a maximum directed dose, this may explain the global difference in adherence. The ‘as needed’ use of NSAIDs and analgesia needs to be clearly defined in this type of research so that it is considered in terms of the directions given to patients, some of whom may define themselves as non-adherent if they believe they have to take an NSAID regularly despite being given ‘as needed’ directions.

Among lupus patients, Petri et al. [15] used a physician’s opinion to categorize patients as adherent or not, with some evidence in hospital records only required to confirm non-adherence. Patients of Afro-Caribbean origin were more commonly categorized as non-adherent (56%) than white patients (34%), and this was thought to explain poorer renal outcomes in the Afro-Caribbean group. In contrast, in Mosley-Williams et al.’s study [16], in which patients themselves stated whether they failed to take prescribed medication all the time or did not fill any prescriptions, no difference between Afro-Caribbean and white lupus patients was observed. Only 10% of both racial groups were globally non-adherent. This gross difference in racial variability in adherence between these studies is likely to be an artefact of the completely different operationalizations and requires comparison in future samples. Cultural differences in adherence are possible if socioeconomic differences in material wealth and location impact on access to health-care [15], or if cultural beliefs and perceptions about medication taking vary across groups.

The extent of adherence among lupus patients also appears to depend on the medications prescribed. McElhone et al. [17] reported that the prevalence of perfect adherence (always taking the medication as prescribed) among white women with lupus ranged from 100% for azathioprine and 94% for oral steroids to 68% for NSAIDs and 61% for bone-protective medications. Lower adherence may relate to stringent recommendations for the way the latter should be taken [18] and the way the relative
importance of medications is communicated by health professionals and perceived by patients. Adherence estimates in rheumatoid arthritis (RA) patients are similarly variable. Neame and Hammond [19] found 92% of RA patients disagreed with the single statement ‘I often do not take my medicines as directed’. Adherence rates among RA patients also depend on the type of medication. Across a 3-year period, Villet et al. [20] found the proportion of RA patients who answered they stick ‘very strictly’ to both dose and timing of their medications was 55% for NSAIDs, 59% for DMARDs and 65% for oral steroids. Using electronic dispenser monitoring over one month, Park et al. [21] found only 38% of RA patients showed perfect adherence across all medications, with no dose omissions or commissions in any one day. This may also vary between medication classes: using the same definition, called ‘correct dosing’, de Klerk et al. [22] found adherence of around 70% for NSAIDs, 55% for sulphasalazine and 81% for methotrexate over 6 months. A more stringent assessment of adherence using ‘timing compliance’ (the number of inter-dose intervals of the prescribed duration ±25%) found that adherence rates were around 40-50% for NSAIDs, 25% for sulphasalazine and 83% for methotrexate. Electronic dispenser monitoring is costly and methodologically complex [22], and when participants know they are being observed they may increase their actual adherence or fake it. However, the less demanding, weekly regimen for methotrexate may facilitate enhanced adherence. In addition, these figures suggest that patients may not be as dependent on NSAIDs as is thought, and their sparing use may actually be advantageous in the light of recent concerns about the cardiovascular safety of continuous high-dose use of these drugs [23].

The presented prevalence figures for adherence to anti-rheumatic medications are not adjusted for disease activity, which is likely to be high among patients requiring DMARDs. In our cross-sectional investigation of this issue [24], we found weak, non-significant correlations between self-reported adherence and inflammation (C-reactive protein levels and erythrocyte sedimentation rate) in RA patients. This does not discount the possibility of more subtle processes that may lead to fluctuating associations of disease activity and adherence over time within the same individual.

Consistent adherence would be expected for the highly desired anti-TNF therapy, but may depend on the route of administration [25]. Around 25% of RA patients on home-administered subcutaneous anti-TNF reported not taking it regularly in an Italian study [26]. The reasons for this non-adherence are unclear, but more than 60% of those who missed a dose did not contact a health professional beforehand. Lack of an arranged communication procedure may amalgamate with the presence of a side-effect or other concern to lead to non-adherence to anti-TNF treatment.

There are currently a number of self-report, multi-item questionnaire-based measures of medication adherence employed in research on this topic. Morisky et al. [27] devised a scale consisting of four questions on reasons for non-adherence, which are answered with a yes/no response. Internal consistency of the four varied questions tends to be lower than acceptable, hence researchers resort to using individual items or specific combinations of items when using this measure [28]. A more recent measure is Horne et al.'s Medication Adherence Report Scale (MARS) [29]; available at: http://www.medicines-partnership.org/projects/evaluation-toolkit, which consists of five non-adherence behaviours that are mainly intentional and are rated for frequency on a five-point scale. The MARS has good internal consistency [29]. However, neither of these self-report measures performed well compared with electronic dispenser monitoring (over 6 weeks) in transplant recipients taking oral steroids and immunosuppressants (medications which many rheumatology patients also take) [29].

The Compliance Questionnaire – Rheumatology (CQR [30, 31]) is currently the only rheumatology-specific compliance/adherence measure. The 19-item CQR was derived from patients' statements by de Klerk et al. and is answered on a 4-point Likert scale. Although less parsimonious than the MARS and Morisky scale, the CQR compares well with electronic dispenser monitoring over 6 months [31]. Responses to the CQR items are summed to provide a total score that can be treated statistically as interval level data, allowing more powerful statistical comparisons of predictors or effects of medication adherence than simple dichotomy responses or unbalanced categorizations.

Beliefs about medications (Table 1) have social and psychological roots, and are consistently important for adherence. Among RA patients, those who believe their medications are necessary to stick to taking their recommended treatment, barring errors (after [9]). The (still paternalistic) view that the informed (but still passive) patient will stick to taking their recommended treatment, barring errors (after [13]) leading to an agreed treatment and ongoing assessment of this as the optimal course (after [42, 43])

The process of enlightened communication between the patient and their health-care professional; leading to an agreed treatment and ongoing assessment of this as the optimal course (after [42, 43])

Beliefs about medications Perceptions of one’s need for medication balanced against personal and general concerns about medications (after [65])

Self-efficacy Belief in one’s ability to exert control over an outcome (after [66])

TABLE 1. Definitions and recommended measures of key concepts around medication-taking in rheumatology

<table>
<thead>
<tr>
<th>Concept</th>
<th>Summary definition</th>
<th>Recommended measure</th>
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<tbody>
<tr>
<td>Compliance</td>
<td>The paternalistic view that the patient is a passive party who has their prescribed treatment enforced (after [9])</td>
<td>Serum concentration of a tracer in the medication [38]</td>
</tr>
<tr>
<td>Adherence</td>
<td>The (still paternalistic) view that the informed (but still passive) patient will stick to taking their recommended treatment, barring errors (after [13])</td>
<td>The Compliance Questionnaire – Rheumatology (CQR [30, 31])</td>
</tr>
<tr>
<td>Concordance</td>
<td>The process of enlightened communication between the patient and their health-care professional; leading to an agreed treatment and ongoing assessment of this as the optimal course (after [42, 43])</td>
<td>The Leeds Attitude To Concordance scale (LATCon [57])</td>
</tr>
<tr>
<td>Beliefs about medications</td>
<td>Perceptions of one’s need for medication balanced against personal and general concerns about medications (after [65])</td>
<td>The Beliefs about Medications Questionnaire (BMQ [33, 34])</td>
</tr>
<tr>
<td>Self-efficacy</td>
<td>Belief in one’s ability to exert control over an outcome (after [66])</td>
<td>The Arthritis Self-Efficacy Scale (ASES [67, 68])</td>
</tr>
</tbody>
</table>

The ASES measures perceived control over pain, fatigue, function and mood; extension of this scale to cover patients and health-care professionals' perceived ability to achieve concordance/adherence would be theoretically and operationally useful.
Therapy Concerns Questionnaire [37], but these are yet to be employed and evaluated among rheumatology patients.

Improving RA patients’ self-efficacy (Table 1) has been linked with better medication adherence. Strong interventional evidence was produced from Hill et al.’s [38] unique randomized controlled trial. Self-efficacy education had a positive effect on adherence, which was measured using a tracer in standardized medication. This is an impartial way to assess adherence but is also costly and cannot fully determine timing [22]. Elliott et al.’s recent systematic review [3] concluded that further high-quality studies are required to substantiate the claim that medication adherence interventions are cost-effective. Such interventions may be even more effective if reframed around the concordance philosophy [39] that we describe below.

The term ‘adherence’, although slightly less paternalistic than ‘compliance’, also implies an imbalance of power, wherein the health professional recommends a particular course of action to be followed, regardless of the patient’s opinion. Generally, the health professional has the greatest disease knowledge and therefore advises the patient on the best known treatment appropriate for the level of illness. This decision is balanced against risks and grounded in the latest evidence-based, locally tailored guidelines and experience (e.g. [40]). However, ultimately it is the patient who has their health compromised and who has to live with the disease and medication-taking.

The use of the term ‘concordance’ is growing in the context of medication-taking and literally means ‘together–heart’ and refers to ‘agreement’ or ‘harmony’ ([41], section 1) or establishing a treaty ([41], section 2). This eloquently captures the interactional decisional processes needed to promote partnership between patients and health professionals that the NHS is currently working towards [42, 43] by creating a therapeutic alliance to ‘optimise health gain from the best use of medicines, compatible with what the patient desires and is capable of achieving.’ (p. 12, original emphasis [42]).

Although discordance can exist in a consultation, this must be resolved through compromise or agreeing to disagree [44], the patient having the final say on the ‘concordat’ (which philosophically replaces the prescription). The term ‘intentional non-compliance’ is thus futile and non-adherence to the concordat is only possible through failures in communication, accurate recording or memory, from either party.

A patient who chooses to stop a medication if there is a potentially serious side-effect (e.g. infection) without seeking medical advice can be seen as both non-adherent and non-concordant. Side-effect concealment has been found to occur among RA patients on DMARDs and anti-TNF therapy [26, 35, 45]. Concealment is likely to reflect a perception that the necessity of the medication outweighs the side-effect [35, 45], and may indicate a lack of effective communication with patients and other health professionals, especially general practitioners (GPs). Careful guidelines and information for patients could facilitate more optimal health outcomes in scenarios such as these.

At present, concordance may not be a familiar concept (or descriptor) for either patient or health-care audiences, so it needs to be explained in order to facilitate the process itself and distinguish it from other meanings (e.g. concordance of diseases in twins or between raters of a phenomenon).

Concordance is particularly relevant when two or more possible interventions exist and have approximately equal chances of benefit [46, 47], and when the potential benefits and risks of these interventions cannot be accurately predicted for the individual (as is the case in most of clinical practice). Concordance is therefore very applicable in rheumatology, particularly in the anti-TNF era [48]. Despite this, research touching on concordance is rare in rheumatology (e.g. [49–51]) even though the topic has been subject to media attention (e.g. [52]).

A patient’s decision about their level of involvement is important to the concordance process [53]. Some patients want to defer decisions entirely to their health professionals or family members. It is therefore essential to openly enquire about patients’ desired level of involvement and test whether patients who defer their treatment decision then actually take the medication they are recommended as accurately as patients who have contributed to the decision.

Research by Doherty and Doherty [54] shows that few medical and surgical in-patients preferred a totally active role in their treatment decisions. A slight majority of medical patients preferred a collaborative role, while a slight majority of surgical patients preferred a passive role. Such research merits extension in a homogeneous sample. Osteoarthritides would be an appropriate population to address this among as they often progress from management by medication-taking to requiring arthroplasty [55].

Research with RA patients by Neame et al. [50] shows that 78% felt patients should feel free to make ‘everyday’ decisions about medical problems, but 75% felt doctors should make ‘important’ medical decisions. Over 50% felt patients should go along with this decision even if they disagreed with it (i.e. a failure in concordance). Qualitative research has highlighted the importance of involvement in consultations for RA patients [51]. While the study by Lim et al. [49] found that 94% of RA patients felt they were involved in the decision-making process, only 34% of these patients altered the amount or frequency of their medications. Traditionally this would be conceptualized as non-adherence but may reflect active decision-making [56]; it would not be seen as non-concordance—so long as patient–professional communication is maintained.

Two questionnaires have been purposefully designed to measure the achievement of concordance, ironically without any apparent patient involvement. Raynor et al.’s [57] Leeds Attitude To Concordance scale (LATCon; available at: http://www.medicines-partnership.org/projects/evaluation-toolkit) contains 12 items answered on a four-point Likert scale. The LATCon is an internally consistent unidimensional scale [57, 58]. Research employing this scale shows that, among patients attending their GP, concordance is achieved to a greater extent among women than men and younger rather than older patients, but its achievement does not relate to the number of GP consultations over the previous year [58]. Stiggelbout et al.’s [53] Ideal Patient Autonomy Scale (IPAS) contains 14 items answered on a five-point Likert scale. The IPAS has four independent, reasonably consistent subscales: ‘obligatory risk information’ (two items), ‘right to non-participation’ (three items), ‘doctor knows best’ (five items) and ‘patient should decide’ (four items). These scales also require rheumatology-specific revalidation but will be useful tools for comparison with patient-generated questionnaires. Such scales need to be applied both in observational studies and trials of concordance interventions in rheumatology. One important issue is to highlight the anonymity of participants (both patients and health-care professionals) in studies of concordance. It may be salient to ensure researchers are a neutral party (external to clinical health-care) to facilitate free expression of opinions that may or may not be favourable. Moreover, the traditional doctor–patient set-up is changing with moves towards nurse and pharmacist prescribing [59]. Perceptions of these roles will be an interesting comparator, given the different location and duration of interaction they may involve.

The paternalistic approach to health-care provision, as exemplified by the term ‘compliance’, is patently not achieving high rates of uptake and this may have significant implications for the individual patient and for health-care providers. In the current era of free and easy access to information and a generally higher educational and socio-economic level across the population, the concept of concordance seems to be a worthy goal. However, in order to facilitate the very process of concordance, we need to investigate how to teach active discussion and negotiation skills to both patients and health professionals. This teaching is included
in the British National Expert Patient Programme [60] and has been shown to be effective in an intervention for undergraduate medicine teaching [61]. It may also be useful for continuing professional development in rheumatology, but needs to be studied in this specific context and more widely. While the concept of concordance ties in with current moves to ‘patient-centredness’ in the NHS [62] and other nations’ health services [63, 64], we will not know the balance of its costs and benefits for rheumatology until research is carried out and evidence accumulates on the process and its effects. Perhaps concordance will turn out to be beneficial only for patients with certain diseases or particular kinds of treatment options, or simply for certain patients and not others. For example, the concordance approach may be more successful when dealing with high-cost or high-risk medications or among patients with good pre-existing knowledge about the illness and treatment or low trait anxiety. Achieving genuine concordance is likely to be a time- and resource-consuming process. Concerns about professional responsibility may also be an issue when applying the concordance approach; health professionals may worry about their accountability for negative outcomes following a null condordat when their suggested treatments are rejected by the patient. On the other hand, do health professionals feel accountable following a paternalistic consultation which leads to a patient’s non-concordance? While the outcome is the same in both situations (no treatment), with the latter situation it seems much easier to place the burden of responsibility onto the individual patient. In conclusion, the moral, communicational, educational, logistical and health-economic (cost-effectiveness) implications of attempting to apply the concordance approach need to be carefully considered and accurately assessed in future studies. The sooner solid research is conducted on achieving concordance in rheumatology, the better for all concerned.

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