2020 EULAR points to consider for the prevention, screening, assessment and management of non-adherence to treatment in people with rheumatic and musculoskeletal diseases for use in clinical practice

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ABSTRACT

Background Non-adherence to treatment could preclude reaching an optimal outcome. Thirty to 80% of patients with rheumatic and musculoskeletal diseases (RMDs) do not adhere to the agreed treatment.

Objectives The objective was to establish points to consider (PtCs) for the prevention, screening, assessment and management of non-adherence to pharmacological treatments in people with RMDs.

Methods An EULAR task force (TF) was established, and the EULAR standardised operating procedures for the development of PtCs were followed. The TF included healthcare providers (HCPs), comprising rheumatologists, nurses, pharmacists, psychologists, physiotherapists, occupational therapists and patient-representatives from 12 European countries. A review of systematic reviews was conducted in advance to support the TF in formulating the PtCs. The level of agreement among the TF was established by anonymous online voting.

Results Four overarching principles and nine PtCs were formulated. The PtCs reflect the phases of action on non-adherence. HCPs should assess and discuss adherence with patients on a regular basis and support patients to treatment adherence. As adherence is an agreed behaviour, the treatment has to be tailored to the patients’ needs. The level of agreement ranged from 9.5 to 9.9 out of 10.

Conclusions These PtCs can help HCPs to support people with RMDs to be more adherent to the agreed treatment plan. The basic scheme being prevent non-adherence by bonding with the patient and building trust, overcoming structural barriers, assessing in a blame-free environment and tailoring the solution to the problem.

INTRODUCTION

Thirty to 80% of people with rheumatic and musculoskeletal diseases (RMDs) do not follow the recommended treatment plan.1–3 Non-adherence equally affect medication, non-pharmacological interventions and keeping follow-up appointments and are associated with worse outcomes, increased risk of cardiovascular disease, decreased functioning and loss of health-related quality of life.1–7 Strategies to reduce non-adherence are thus essential to achieve an optimal outcome.4–6

The problem of non-adherence is addressed in some EULAR recommendations on the management of specific health conditions or in the role of professionals, but none specifies interventions in or actual directions on how to improve non-adherent behaviour.5–11 All these recommendations focus on specific aspects of non-adherence and do not cover the multifaceted nature of this phenomenon, such as its detection or assessment.

Although general recommendations are lacking, a large number of studies have tested various interventions targeting non-adherence, including screening and assessment of non-adherence,1 provision of equitable and coordinated access to treatment through, for example, flexibility in scheduling or financial resources according to the respective health system,12 integration of patients in treatment decisions,12,16 enhancement of patients’ autonomy,13 stratification and individualisation of interventions based on the needs and preferences of patients including psychosocial markers,8,9 information and education,10–13 systems to remind patients about appointments, intake of medication and exercises whenever necessary,14 compatibility of treatment interventions to the daily routines of patients,9,13 and offer opportunities to get in touch with other individuals with similar health conditions or other social support.12,13 Interventions are delivered by rheumatologists, other medical specialists, general practitioners or health professionals in rheumatology (HPRs) (ie, nurses, pharmacists, physiotherapists, occupational therapists and psychologists) in close collaboration with each other in primary and secondary care settings.

The objective of the present work is to establish points to consider (PtCs) for the prevention, screening, assessment and management of non-adherence in people with RMDs for use in daily clinical practice.

The users of these PtCs are intended to be rheumatologists and HPRs (together will be referred as...
healthcare providers or HCPs, patients and caregivers, regulators, trainers and others, at the individual or organisational level (eg, patient organisations, pharmaceutical and/or insurance companies). Regarding their scope, these PtCs are applicable to all RMDs, except those with an acute or subacute course (eg, some viral arthritis), as longer duration of diseases increase the chances of non-adherence. In addition, the scope of the PtCs does not include children and adolescents, as their non-adherent behaviour differs from that of adults, mainly on its great reliance on social support of caregivers. We acknowledge that different RMDs may have specific problems—for example, non-symptomatic conditions, such as osteoporosis, pose additional challenges to motivate a patient to follow a long-term prescription (prescription in this context refers to any instruction (mostly written) from a physician or health professional in rheumatology stating the form, dosage and kind of treatment, including but not limited to medications, exercises, diets and follow-up appointments); however, non-adherence affects them all, and only very exceptionally a PtC for an RMD might not apply to another.

In addition, these PtCs only refer to non-adherence to pharmacological or non-pharmacological treatments that are prescribed or recommended. They are not including non-adherence to lifestyle changes, such as diet, weight loss and smoking or to visit schedules. Regarding medication, the task force decided that symptomatic medicines may not be the specific objective of these PtCs, and that non-pharmacological treatments should be restricted to exercises and medical devices (eg, splints). Exercises may be defined as a type of physical activity that is planned, structured and purposeful.

Finally, in the context of these PtCs and following the definition of the WHO, non-adherence is defined as the extent to which a person’s behaviour does not correspond with the agreed prescription, of pharmacological or non-pharmacological treatments, by an HCP. Besides being intentional or non-intentional, non-adherence (1) may occur at the start of treatment (initial non-acceptance), and so the patient never collects the prescription, or does not sign up to exercises, and hence does not follow any of the prescription; (2) may be a result of a poor execution, either by taking an incorrect dose, taking the drug at a wrong time or by decreasing or increasing the frequency of doses (or their equivalents in exercises or the use of medical devices) or (3) may be due to discontinuation of the treatment at any time during the treatment course.

**METHODS**

These PtCs were developed according to the consensus process suggested by the EULAR Standard Operating Procedures. An international expert task force was established bya steering committee(10,18),(991,993) (LC, VR, AdT and TAS), and included people with RMDs (n=2), EMEUNET members (n=3 (AM, RGD and VR)), and representatives from relevant HCP groups: nurses (n=3), occupational therapists (n=2), psychologists (n=3), physiotherapists (n=1), pharmacists (n=2) and rheumatologists (n=6), all of whom had various levels of expertise in the field of non-adherence and came from a broad geographical distribution across Europe. A systematic review (SR) of reviews and meta-analysis on existing strategies to prevent or mitigate non-adherence, supervised by the methodologist and the convenors, was presented at a first task force meeting (the SR is subject of a separate publication). In this meeting, the scope, users, structure of the document and overarching principles were established by nominal group technique, as well as additional clinical questions to be addressed by SR. These clinical questions were converted into Population Intervention Comparison Outcome questions by the convenors (LC and VR), methodologist (AdT) and research fellows (VR and JBN), and the search strategies developed, by an experienced Librarian, in Medline, CINAHL, web of science, science direct and the Cochrane Database of SR. The quality of the selected reviews was assessed using ‘A MeaSurement Tool to Assess systematic Reviews’ (available at https://amstar.ca/). The quality and risk of bias of the original studies were obtained directly from the published reviews (ie, Cochrane’s Risk of Bias tool for intervention studies and QUADAS-2 for assessment studies). Because of the high heterogeneity, the evidence was synthesised qualitatively. In a second meeting of the task force, the results of the SR were discussed and the PtCs were formulated. Data from the SR were categorised according to the Oxford system for levels of evidence, and statements were voted and discussed using a three round Delphi technique. Level of agreement (LoA) voting was scored anonymously (www.sli.do) on a numerical rating scale ranging from zero (completely disagree) to 10 (completely agree). The first two Delphi rounds were performed during the second task force meeting. Agreement in the Delphi was defined as >80% of experts within the task force voting in favour (nine or 10) or against (one or two) an item. Items with agreement against were excluded from the list. Items with agreement in favour were maintained without further voting, unless reformulation was proposed. All intermediate items and those that needed reformulation were voted in a second round. Finally, in the third Delphi round (done by electronic communication (www.surveymonkey.de)), task force members were asked to give their final rating on every point to consider. All members of the task force were asked to respond during each round.

**RESULTS**

The results of the taskforce efforts are divided into four overarching principles and nine PtCs. The difference, in absence of strong evidence, is that overarching principles are not suggestions on what to do, but more principles to understand why and how the following points are formulated. They are explained and justified in detail below and presented in table 1 with the accompanying level of evidence (LoE), grade of recommenda-

**Overarching principles**

**Overarching principle A: adherence impacts the outcomes of people with RMDs**

In RMDs, non-adherence has been associated with worse disease severity, increased pain and fatigue, higher rates of depression, lower function and a decrease in quality of life and physical activity.

**Overarching principle B: shared decision making is key, since adherence is a behaviour following an agreed prescription**

Ideally, patients and their HCPs should agree on the recommended treatment, including duration, dosage and frequency of medication intake, or exercises or device use over a period of time. To make an informed decision, patients need to understand their choices (ie, shared decision making, or SDM). The SDM process has been defined as ‘an approach where HCPs and patients share the best available evidence when faced with the task of making decisions, and where patients are supported to consider options, to achieve informed preferences’. During the SDM process, mutual expectations in terms of efficacy, safety and monitoring should be discussed, as well as fears and
necessities about the specific treatment. The patient should be informed about the need to be adherent and how adherence will be evaluated. Agreement is part of the definition of adherence in the sense that if the patient did not agree to start with, it could not be considered non-adherence. Although, SDM is ambitious in systems with time constraints and low availability of professionals, it cannot be overlooked if we want to act at all on non-adherence.

Overarching principle C: adherence is influenced by multiple factors

Patients may have comorbidities, multiple treatments, circumstances, cognitions and preferences that need to be taken into account, when addressing non-adherence. Health systems are complex and, in each setting, different HCPs may have different roles. These PtCs have an integrative approach that goes beyond the clinical encounter, as they stress that all, HCPs and patients, are involved in the care of patients.

Overarching principle D: adherence is a dynamic process that requires continuous evaluation

Patients’ beliefs and fears about prescribed treatments, as well as behaviours, are influenced by experience and by external and internal determinants, for example, depression, other comorbidities, side effects, lack of efficacy or life changes that pose logistic hurdles. We cannot assume that a person will continue to be adherent or non-adherent to any given treatment, and that this will be maintained and stable across prescriptions.

Points to consider

PtC 1: all HCPs involved in the management of people with RMDs should take responsibility for promoting adherence

Effective interventions to reduce non-adherence in RMDs were reviewed by our group, and we confirmed that HCP, both physicians—namely, rheumatologists, GP and orthopaedic surgeons—and HPRs—such as nurses, physiotherapists, occupational therapists, psychologists, exercise physiologists, patient educators and pharmacists—were involved in the delivery of these interventions. Nieuwlaat et al underscore in their Cochrane review that nurses, pharmacists and therapists are increasingly becoming part of delivering interventions that target non-adherent behaviour in people with RMDs. This PtC gives responsibility to the full care team. It highlights both the relevant role of these HPRs and also both the need to acknowledge their efforts, and to coordinate teams beyond the rheumatology clinic. Training in specific interventions—for example, motivational interview or communication skills—may also be behind effective or non-effective interventions. Very importantly, the HCPs should be involved and should be trained as well.

PtC 2: effective patient-health professional communication should be applied to enhance adherence

An overview of SR on strategies proven effective to reduce non-adherence to medication and prescribed exercises found that effective communication was part of most multifaceted interventions proven successful. Unfortunately, the content and nature of effective communication is not well detailed. Despite the absence of consensus on a definition of effective communication, its components—namely, empathy, open questions or bilateral feedback, among others—were discussed and detailed by the task force (see online supplemental table S3). Very importantly, as effective communication helps build trust with the patient and ensures a proper transmission of information about the condition and treatment, it should be in place before the point at which the prescription is discussed.

PtC 3: barriers and facilitators of adherence of a specific patient to a specific prescription should be appropriately evaluated

Many different factors determining non-adherent behaviour in people with RMDs have been identified in many studies, covering various domains. The WHO generated a framework by which these factors were classified into five different domains: (i) patient-related, (ii) condition-related, (iii) therapy-related, (iv) the socioeconomic context and (v) the healthcare system. Our overview of SR of qualitative studies demonstrated that the list of barriers and facilitators is extensive, with many factors not being modifiable, and none of them being a sole predictor of non-adherence.
Some factors change with time and can appear either to be a cause, or a consequence, of patient non-adherence (eg, depression can lead to less motivation to adhere, but it can also be a consequence of disease activity due to non-adherence). Barriers to adherence are considered complex and multi-faceted and non-adherence should never be perceived as patients’ fault only (eg, the hospital pharmacy was not open the only day a patient could take off from work that month, or the patient’s skills for self-injection are very limited). Based on the overview SR,19 we have produced a checklist of factors related to non-adherence, which could help HCPs to identify barriers to adherence at the individual level (see online supplemental table S1).

PtC 4: patient education should be provided for people with RMDs as an integral part of standard care

Most interventions with proven effectiveness in non-adherence include components of patient education,19 namely provision of knowledge or information, self-management programmes, cognitive behavioural interventions, mindfulness, stress management, individual consultations, sharing experiences among patients, motivational discussions, exercise counselling, lifestyle change interventions and self-help courses. With this PtC, the task force wants to emphasise that ‘all people with RMDs should have access to and be offered patient education throughout the course of their disease including as a minimum: at diagnosis, at pharmacological treatment change and when required by the patient’s physical or psychological condition’.31

Of course, we cannot overwhelm the patient at diagnosis or treatment start with information, but studies agree in that patient education, either direct or supported via websites,29 30 brochures, SMS24 23 or e-health may reduce non-adherent behaviour. In order to be effective, education/information should include information about drugs,31 32 disease processes,31 32 physical exercises,31 joint protection,31 33 pain control,31 33 coping strategies31 and lifestyle changes.32 33 Delivery formats can include verbally (face to face31 or by telephone34), written (as leaflets31 or using test messages29 30) and visualised in charts35 (see online supplemental table S2).

PtC 5: care should be tailored to patient preferences and goals to enhance adherence

As already mentioned, the list of potential factors that can influence non-adherence to treatment is extensive and challenging to address. However, building a trust and a sound patient–HCP relationship will prepare the scene for a responsible and blame-free framework that will reduce non-adherence in the long term.28 This tailored care has a maximum exponent during the SDM process, when options and patient preferences are the basis for an agreement to be treated and monitored.

PtC 6: adherence should be discussed regularly based on open questions and particularly when disease is not well controlled

As adherence changes with time, the task force could not specify a best moment to assess non-adherence. Finally, we suggest that non-adherence should be assessed in a continuum. The task force discussed the opportunity to discuss non-adherence when the disease is not well controlled but specifically agreed to highlight the need for regularity. Regularly in this context would be, at a minimum, once per year.

Some experts within the TF argued to use validated measures of non-adherence, for instance, by the Medication Event Monitoring System, the level/dose ratio or the medication possession ratio.38 The reality is that the non-adherence construct has many grey areas and more than 200 ways to measure non-adherence to medication exist.37 The TF undertook an SR of instruments to screen non-adherence to medication and exercises in people with RMDs, including but not limited to validated questions, questionnaires, assessment and others (eg, pill counts, worn splint), without identifying a single measure that was clearly superior, neither for medication nor for exercises.19

In practical terms, whether non-adherence is a problem or not, it should be discussed through open conversation with the patient. The ‘some people’ approach may facilitate the generation of a safe space for more elaborated questions and answers (‘We know it can be difficult, everybody has some problems, could you tell me what problems you encountered when taking your medication?’ or ‘Could you show me how you actually wear the splint? How do you actually perform the exercises?’).38 Other forms of screening, like questionnaires, looking at pharmacy indicators, drug levels or wearables can be used, always tailored to patient preferences and goals to reduce non-adherence, but a single measure without the open discussion is not recommended.

PtC 7: the HCP should explore which factors might negatively influence adherence, including opportunity (eg, availability or cost), capability (eg, memory problems) or motivation (eg, concerns)

This PtC adds a method or systematic approach to explore barriers to adherent behaviour. We used the Capability, Opportunity and Motivation model of Behaviour (COM-B) as framework to explore patient’s drivers for non-adherence and as instrument to identify possible targets for reducing non-adherence.30 The model acknowledges that behaviour is part of an interacting, dynamic system involving these components to determine a person’s non-adherence. The problems that are easiest to address are those of practical nature—for example, unavailability at local pharmacy, pharmacy open hours, interference with occupation—and thus they should be the first ones explored. Next would be knowledge or capability related, for example, the patient does not really understand the duration of treatment, what to do in case of missing dose, or how to inject. These can be explored by asking the patient, with some level of detail, how she or he actually takes the medication or, in the case of exercises, how he or she performs the exercises. Regardless of problems in these previous areas, the motivation to adhere, or intention, has to be explored. This is usually explored in terms of needs and concerns.

PtC 8: together with the patient, the HCP should tailor the approach to overcome individual barriers to adherence, for example, simplifying the regimen, using reminders, providing education, discussing the patient’s beliefs on treatments

Based on the reasons for non-adherence, the solutions must be tailored to tackle the specific problems. There is not general recipe or ‘one size fits all’ as how to do this and solutions to tackle non-adherence are plenty. The two steps of a tailored approach would be (1) to identify the reasons of non-adherence, including the assessment of problems, as well as low health literacy or skills, and (2) to focus on the specific problems, modulating the intervention to the individual (eg, a patient clearly needs a reminder but does not have a smartphone, we should recommend the use of pill boxes with timers). Some randomised controlled trials that specifically named their strategies as ‘tailored’ showed positive results.32 34 39–41 Many include revising treatment schemes to make them as convenient and easy to follow as possible. Besides patient education strategies, already highlighted, there are simple things that can be done, like advising on cueing.
behaviours (eg, pairing medication taking with an established behaviour, such as brushing teeth), monitoring (eg, using a calendar or a diary to track medication taking), including the family and close ones in the intervention, review plans/strategies and give feedback (including positive reinforcement) and answers. Individualising the prescription and regimen according to the preferences and goals of the patient has been proven effective. In the case of exercises, it has been suggested to split treatment visits, increase proxy efficacy (ie, patients’ confidence in the therapist’s ability to function effectively on his/her behalf; this can be done by showing that the therapist competency really aids achieving goals) and discuss barriers and facilitators of exercises with the patient, encouraging him/her to plan own treatment regimens, discussing intentions and helping recasting unrealistic plans, individualising physical activity advice, tailoring graded exercise programmes, training in the proper execution of physical exercises and providing visual media of the prescribed exercises and explanatory written information. A list of practical things is shown in the online supplemental table S2.

PIC 9: when specific expertise or interventions for adherence are needed, they should be made available to patients
Some interventions, especially those related to avoid intentional non-adherence may need specialised skills, such as motivational interviewing. If the care team includes a psychologist, she or he should be ideally involved, either in the management of the individual patients or as trainer or consultant for the team members. Other skills, such as being able to deliver effective communication, are insufficiently incorporated in most teams.

DISCUSSION
The topic of non-adherence is of utmost importance and yet not adequately addressed in rheumatology. Non-adherence both results in poorer outcomes and also in increased resource use and medical costs. Non-adherence varies across RMDs, being critical in gout and osteoporosis, but also in rheumatoid arthritis, where it even vary across medication. The work of this multidisciplinary taskforce has highlighted both the complexity and a possible practical approach to non-adherence to prescribed treatments in RMDs.

The WHO definition of adherence does not easily translate into operational terms, as it relates to a behaviour. Non-adherence can take many different forms: the patient could actually be overdosing the medication, the exercises or the use of devices, or not using it as prescribed (eg, misapplying medication or exercises, or using splints ineffectively). The complexity and difficulty of identifying factors accurately and predicting medication non-adherence has led to the development of cognitive models to better explain this complex phenomenon. These models take into account areas such as illness beliefs, expectations, barriers and intentions, and have become the basis of measurement instruments. In practical terms, and in the context of a frank discussion, we should ask the patient about his or her beliefs and concerns about treatments, as these are universally present in patients on long-term treatments. In this line, Føt et al found a moderate effect of pharmaceutical treatment necessity in rheumatoid arthritis and systemic sclerosis—both being the RMDs with largest ‘need’ belief of treatment—and lowest in osteoporosis, while they found a strong negative association between concerns about adverse effects of taking medicines and non-adherence in rheumatoid arthritis and in osteoporosis and moderate in systemic sclerosis. Patients will always weigh up necessity and concern, and therefore we have a ‘window of opportunity’ for patient education and counselling.

Patient-centeredness and shared decisions are key elements in relation to (non-)adherence. If perspectives and preferences of patients are not adequately taken into account in medical decisions, non-adherence might get a paternalistic connotation. Instead the HCP ‘telling’ the patient what to do and the patient needing to follow this advice, a common patient-centric perspective should be established, and patients should be encouraged to take active role in the subsequent decision. However, we acknowledge that it is not possible for HCPs to assess or be certain that a patient has agreed to the proposed treatment plan, especially because some patients may give socially desirable answers (for fear of disappointing the HCPs). Therefore, adherence should be discussed regularly, and the patients must be given assurance that they can be honest, because it is their right not to take the treatment as prescribed. However, the patients should also be encouraged to tell the HCPs about not taking the treatment as only with mutual trust, optimal can take place.

The aim of our taskforce was to be as practical as possible. Other groups have already issued recommendations to reduce non-adherence in RMDs, but they dealt specifically with medication and rheumatoid arthritis, and we wanted to be broader. A practical local initiative designed a model for prescription to tackle non-adherence, and in a very practical paper, Rashid et al synthesise the implications of qualitative research in the field of non-adherence into the following 11 statements: (1) individualise care plan, (2) address practical barriers for the individual, (3) adopt a patient-centred approach, (4) increase HCPs involvement, (5) ensure long-term follow-up, (6) promote self-management, (7) increase family or carer involvement, (8) improve patient education, (9) address system barriers, (10) increase access to non-prescribing HCPs and (11) improve staff training. Many of these suggestions reflect our views and conclusions.

Exercises are a pillar in the treatment of most RMDs and non-adherence may be even larger than to medication. We realise that both the definition of adherence and most of the literature deal with non-adherence to medication, and thus will not entirely apply to exercises or to other prescribed treatments, such as use of splints. However, due to the generic nature of the PtCs, we assume that our results can equally be applied to any treatment the patient is receiving and thus will cover exercises as well.

Two aspects differ from the initial plans of this taskforce. First, prevention was not initially included as an objective of the taskforce; however, it soon became clear that prevention is the ultimate solution to avoid non-adherence, and strategies to achieve it will probably overlap with those of an optimal SDM process. Second, in the proposal approved by the EULAR executive, non-adherence to visits and to diet, and not only to medication or exercises, were initially included. However, the task force thought that visits and diet were too complex to measure, and would overlap with other initiatives, and left them out of the scope and the research agenda.

Finally, regarding the implementation of these PtCs, the task force wanted to stress, on one hand the need to adopt a truly patient-centred approach and, on the other, the need to make system changes. Several PtCs involve the patient as main stakeholder in the issue of non-adherence. Nothing can be done in terms of non-adherence without the help of the one who agrees, or not, to follow the treatment or exercises as prescribed. To engage him or her, we will need to attain basic effective communication skills and make SDM a reality. The consequences will be a better outcome and higher odds of adequate self-management.
Similarly, if we do not evaluate periodically non-adherence, the basic scheme being minimise non-adherence by bonding with the patient and building trust, and by overcoming structural barriers, assess in a blame-free environment and tailor the solution to the problem.

In summary, these PtCs can help HCPs to support people with RMDs to adhere to the agreed treatment plan, the basic scheme being minimise non-adherence by bonding with the patient and building trust, and by overcoming structural barriers, assess in a blame-free environment and tailor the solution to the problem.

Recommendation

In the next sections, we provide a series of recommendations to reduce non-adherence in people with RMDs and to better integrate the patient into the treatment plan. Moreover, we provide a checklist of tasks that should be included in the treatment plan to improve adherence.

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REFERENCES

Recommendation


22 Centre for Evidence-Based Medicine. OCEBM levels of evidence, 2016. Available: https://www.cebm.net/2016/05/ocebm-levels-of-evidence/


### Table S1. Comprehensive checklist of adherence problems for adaptation to clinical practice

#### Before starting any prescription (prevention)

<table>
<thead>
<tr>
<th>Question</th>
<th>Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Did you apply effective communication strategies?</td>
<td>Empathy + open questions + avoiding gibberish and jargon + bilateral feedback + encourage the patient to share his/her perspective and experience + concordance</td>
</tr>
<tr>
<td>Did you build a trust in the patient?</td>
<td></td>
</tr>
<tr>
<td>Was the transmission of information about condition adequate?</td>
<td>Consider aspects such as age, gender, ethnicity, and educational level</td>
</tr>
<tr>
<td>i.e., did you pay attention to aligning information about the condition with patient’s beliefs (personal and cultural)?</td>
<td>Any clues on typical coping behaviours in this patient?</td>
</tr>
<tr>
<td>Does the patient accept his/her disease?</td>
<td>Does the patient consider it a stigma?</td>
</tr>
<tr>
<td>Did you test knowledge and education of the patient to adapt the level of information?</td>
<td>Do you speak a different language to your patient’s?</td>
</tr>
<tr>
<td>Do you have clues on the level of forgetfulness?</td>
<td></td>
</tr>
<tr>
<td>In case of an asymptomatic disease, was the patient adequately educated about need for treatment?</td>
<td>Additional efforts may be needed in case of young or very old patients, gout, osteoporosis, or long-term disease.</td>
</tr>
<tr>
<td>Did you make any effort to address comorbidity?</td>
<td>Additional efforts may be needed to detect and address depression, anxiety, polymedication or substance abuse.</td>
</tr>
</tbody>
</table>

#### At the moment of prescribing (prevention)

<table>
<thead>
<tr>
<th>Question</th>
<th>Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Did you apply effective communication strategies?</td>
<td>Empathy + open questions + avoiding gibberish and jargon + bilateral feedback + encourage the patient to share his/her perspective and experience + concordance. Avoid rushing; if time shortage, make an extra-appointment (can be with the nurse) for further explanations.</td>
</tr>
<tr>
<td>Did you build a trust in the patient?</td>
<td></td>
</tr>
<tr>
<td>Was the transmission of information about treatment adequate?</td>
<td>Only check as done once the ones below are checked.</td>
</tr>
<tr>
<td>Does the patient believe in the need of the treatment?</td>
<td></td>
</tr>
<tr>
<td>Did you explain what to expect in terms of effectiveness and regarding time of effect?</td>
<td></td>
</tr>
<tr>
<td>Did you explain what to expect in terms of side effects and acceptability?</td>
<td></td>
</tr>
<tr>
<td>Have you asked about concerns?</td>
<td></td>
</tr>
<tr>
<td>Did you pay attention to aligning treatment with patient’s beliefs (personal and cultural) about the treatment?</td>
<td></td>
</tr>
<tr>
<td>Did you explain the dosage, route, and properties (taste, colour, smell, size…) in lay terms?</td>
<td></td>
</tr>
<tr>
<td>Did you explain the duration of the treatment?</td>
<td></td>
</tr>
<tr>
<td>Question</td>
<td>Consideration</td>
</tr>
<tr>
<td>------------------------------------------------------------------------</td>
<td>-------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Did you pay attention to patient’s support?</td>
<td>Explore any caregiver issues, whether the patient living alone or if the patient has a large burden as caregiver.</td>
</tr>
<tr>
<td>Were reminder systems put in place?</td>
<td></td>
</tr>
<tr>
<td>Is there a provision of service at patient’s location?</td>
<td></td>
</tr>
<tr>
<td>Did you consider patient’s schedule when prescribing the treatment?</td>
<td>Will he/she have time to get infusions / go to pharmacy for refill.</td>
</tr>
<tr>
<td>Did you try to simplify amount of treatment and/or (dosing) frequency?</td>
<td>In case of RA</td>
</tr>
<tr>
<td>Is the treatment prescribed affordable to the patient?</td>
<td>Having other concurrent illnesses affecting adherence</td>
</tr>
<tr>
<td>Could patient history and comorbidity interfere with treatment?</td>
<td>Non-adherence in the past</td>
</tr>
<tr>
<td>Could certain behaviours affect adherence?</td>
<td>Previous treatment failure</td>
</tr>
<tr>
<td>Could there be a discrepancy in the indication between different professionals attending the patient?</td>
<td>Concurrent diseases or illnesses, including malnutrition, psychiatric illness, e.g., anxiety/depression</td>
</tr>
<tr>
<td></td>
<td>Recent hospitalization with long hospital stay</td>
</tr>
<tr>
<td></td>
<td>Both eye blindness</td>
</tr>
<tr>
<td></td>
<td>Impaired motor functioning</td>
</tr>
<tr>
<td>During monitoring (detection and evaluation)</td>
<td>Substance abuse</td>
</tr>
<tr>
<td>Has the patient experience a response?</td>
<td>Injection drugs use (vs. non-injection ones)</td>
</tr>
<tr>
<td>Has the patient experienced any side effects?</td>
<td>Younger age of first marijuana use</td>
</tr>
<tr>
<td></td>
<td>Alcohol abuse</td>
</tr>
<tr>
<td></td>
<td>Smoking</td>
</tr>
<tr>
<td>Does the patient still believe in the necessity of the treatment?</td>
<td>Dermatologist-rheumatologist</td>
</tr>
<tr>
<td>Do you believe in the necessity of the treatment? Should it be changed?</td>
<td>Pharmacist-rheumatologist</td>
</tr>
<tr>
<td>Are there any drugs/interventions that can be prescribed?</td>
<td>Gastroenterologist-rheumatologist</td>
</tr>
<tr>
<td>Are you aware of any system problems?</td>
<td>2nd opinion rheumatologist</td>
</tr>
<tr>
<td>Does the patient have any concern/problems about the treatment?</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Beliefs</td>
</tr>
<tr>
<td></td>
<td>Interference with routines / inconveniences</td>
</tr>
<tr>
<td></td>
<td>Child-bearing prospects</td>
</tr>
<tr>
<td></td>
<td>Costs</td>
</tr>
<tr>
<td></td>
<td>Transportation problems</td>
</tr>
<tr>
<td></td>
<td>Decreased quality of life while taking medications</td>
</tr>
<tr>
<td></td>
<td>Injection formulation or procedure</td>
</tr>
<tr>
<td></td>
<td>Need to adjust dietary habits for taking medication</td>
</tr>
<tr>
<td></td>
<td>Problems with opening containers</td>
</tr>
</tbody>
</table>
### Disliking aspects of the medication
- Poor taste of medication
- Big tablet size, problems with swallowing tablets
- Denial of diagnosis
- Unrealistic expectations concerning the medication’s benefit/risk ratio
- Negative patients’ beliefs about the efficacy of treatment
- Negative attitude toward or subjective response to medication
- Thinking that the treatment could make the patients ill
- Having doubts, or not being able to accept disease
- Unresolved concerns about time between taking the drug and its effect
- “Being tired” of taking medications
- Feeling that treatment is a reminder of disease
- Perceived excessive medication use
- Feeling persecuted or poisoned
- Lack of interest in treatment
- Wanting to be free of medications or preferring a natural approach
- Wanting to be in control
- Prioritizing work over taking treatment

### Does the patient understand the disease and its treatment?

#### Can there be any misunderstanding of the prescription and treatment, instructions, or the consequences of non-adherence?

#### Could there be any misconceptions reported from the media, lay press, family or friends, about a medication?

### Is the patient involved in the management of his/her disease?

#### Would you say he/she is self-efficacious with regard to taking medications?

### Do you know what style of coping behaviour has the patient adopted?

- Non-avoidant coping is OK
- Active coping is OK
- Personality: low conscientiousness, high cynical hostility
- Pessimistic ways of coping
- Withdrawal coping style, or self-destructive escape coping style
- Poor insight
- Lack of self-worth
- Oppositional behaviours
- Laziness/lack of care
- Being too distracted or busy

### Did you make any effort to address comorbidity?

Additional efforts may be needed to detect and address depression, anxiety, polymedication or substance abuse.

### Did you apply effective communication strategies?

Used a ‘no-blame approach’?
Encouraged an honest and open discussion to identify nonadherence and the reasons for nonadherence?

### Is the patient satisfied with the visits?

### Could the time between visits be excessive to monitor effectively toxicity and response?

### Does the patient have access to a quick visit / call in case of a medication problem or doubt?

### Is the treatment plan well structured?
Table S2. List of effective interventions to tackle adherence problems (extracted from synthesis of systematic review [1])

1. Education/information
   - It should include information about:
     o disease process
     o drugs,
     o physical exercise, including:
       ▪ endurance activities (walking, swimming, bicycling),
       ▪ advice on energy conservation
     o joint protection,
     o pain control,
     o coping strategies, and
     o lifestyle changes.
   - It can be delivered:
     o verbally (face to face or by telephone),
     o written (leaflets or text messages), or
     o visually in charts.

2. More consults / time
   - Overcome the constraint of consultation time → 3 goal-oriented visits, with one component of the complex intervention being implemented at each visit.

3. Individualised/tailored treatment according to patient preferences and goals
   - i.e. offering treatment options or exercise in the framework of a SDM process
   - Individualised physical activity advice and tailored graded exercise program according to the preferences and goals of the patient.

4. Frank discussion
   - Patients should have the possibility to express questions and doubts regarding treatment or exercise adherence and have solutions offered

5. Plan
   - Encourage patients to plan their treatment regimens, discuss intentions and help recasting unrealistic plans

6. Train
   - Train in proper execution of physical exercises with photos displaying these exercises and explanatory written information

7. Cueing
   - e.g., pairing medication taking with an established behaviour such as brushing teeth

8. Monitoring
   - e.g., using a calendar to track medication taking
   - Refill reminders
   - Wearables for exercises
   - Apps

9. Positive reinforcement
   - e.g., praising and rewarding with tokens that are exchanged for special privileges.

10. Feed-back
    - Physician and other health professionals should review the plans/strategies developed by the patient and provide feedback and answers to questions.

11. Proxy efficacy (in exercise)
    - Use psychosocial factors relevant for the motivational approach as proxy efficacy.
    - Proxy efficacy relates to the expertise or influence to act on the patient behalf to secure desired outcomes (e.g., I am using proxy efficacy when I feel that my exercise monitor or physiotherapist can assist me in achieving my exercise objectives)
Reference:

Table S3. Components or principles of an effective communication. As there is no consensus on a definition of effective communication, its components were discussed and detailed by the task force.[1-3]

<table>
<thead>
<tr>
<th>Component</th>
<th>Explanation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Empathy</td>
<td>Understanding another person’s experience by imagining oneself in that other person’s situation: One understands the other person’s experience as if it were being experienced by the self, but without the self actually experiencing it.*</td>
</tr>
<tr>
<td>Open questions</td>
<td>A closed question in front of a patient, i.e., with only a yes or not as possible answers, will very surely responded as socially desirable. If we ask ‘Have you taken your medicine right?’ the potential answer will mostly be ‘yes…’, regardless the reality. In contrast, a question like ‘What problems have you experienced taking your medication?’ will elicit a more elaborated response and more sincere, or at least will be easier to detect inconsistencies.</td>
</tr>
<tr>
<td>No gibberish or jargon</td>
<td>When talking to others outside one’s field, even across fields of medicine, the use of technical terms definitely loses the receiver. If necessary, because there are no lay terms for some concept, we should at least use an example to explain what we mean.</td>
</tr>
<tr>
<td>Bilateral feedback</td>
<td>Ask the patient what she or he has understood to check whether your explanation was clear enough and will have the chance to be applied as such, but also summarise what the patient said, to check whether you understood correctly the situation before taking any action to make a diagnosis or to tackle a problem.</td>
</tr>
<tr>
<td>The patient has possibility to share his/her perspective and experience</td>
<td>We tend to ‘overtalk’ during the consultation. If we do not let, and encourage, the patient speaks and explain his or her situation we will not be in the position to adapt our language to the level of literacy, or the treatment to the preferred option, the one that will increase adherence and trust. If we do not give the patient a possibility to speak beyond saying yes or not, we are not doing shared decision making.</td>
</tr>
<tr>
<td>Concordance</td>
<td>Consultations between patients and health care providers most often involve two contrasting sets of health beliefs. Concordance recognises that the health beliefs of the patient, although different from those of the health care provider, are no less cogent or...</td>
</tr>
</tbody>
</table>
PtC on adherence in RMDs

| important when making decisions about the best approach to the treatment of the individual.[4] |

* A distinction is maintained between self and other. Sympathy, in contrast, involves the experience of being moved by, or responding in tune with, another person.

References

Points to consider to promote adherence in people with RMDs

Prevent non-adherence by building trust, overcoming barriers, and tailoring the solution to the problem.

INTRODUCTION
Rheumatic and musculoskeletal diseases (often shortened to RMDs) are a group of diseases that affect the joints and muscles. There are lots of different treatments available that can both treat symptoms, and stop some of the underlying disease processes. Most of these medicines need to be taken regularly for a long period of time.

Not taking medicines, not performing exercises, or not following advice regarding activities and functioning in daily life as prescribed or advised is called non-adherence. People may be non-adherent if they take a different dose than their doctor stated, take the medicine on a different schedule, or use it wrongly. The same applies to non-pharmacological methods.

Adherence is influenced by many different factors. These include the costs of medicines and supplies, the availability of facilities or treatment options, or having the skills needed to do an exercise or take a medicine properly – for example, if it needs to be injected. Adherence can also change over time in the same person. Some people may choose to be non-adherent, and others may just forget to take their medicine or perform their exercises.

Being non-adherent can stop medicines or other treatments working in the way they are supposed to, and may stop you achieving a good outcome from your treatment. Non-adherence is very common in people with chronic diseases. It is estimated that between 30% and 80% of people with RMDs do not adhere to the agreed treatment.

WHAT DID THE AUTHORS HOPE TO DEVELOP?
The authors wanted to write a set of points to consider that could help screen people for non-adherence. They also wanted to be able to give some ideas about how to manage non-adherence.

HOW WERE THE POINTS DEVELOPED?
This was a systematic review done by a group of healthcare providers followed by a consensus of representative experts. The group included rheumatologists, nurses, pharmacists, psychologists, physiotherapists, occupational therapists, and patient representatives from 12 European countries.

A series of points to consider were drafted based on published evidence, and then the group voted anonymously to say how much they agreed with each of the points.

WHAT ARE THE MAIN POINTS?
The group developed four overarching principles and nine points to consider. The overarching principles are designed to help understand how and why the points were included. These acknowledge that adherence has an impact on outcomes for people with RMDs, and is influenced by multiple factors. Shared decision making is important, since adherence is a behaviour and people may be more likely to follow a prescription if they were involved in setting it. Adherence is also a dynamic process that needs continuous evaluation.

ARE THESE POINTS NEW?
Yes. Other groups have issued recommendations to reduce non-adherence in people with RMDs, but they dealt specifically with medication and just one specific RMD (rheumatoid arthritis). These are the first broad points to consider that have been written in this area. They are also novel in that they include non-pharmacological interventions, such as exercise, activity pacing, and give advice on healthy lifestyle.
WHAT ARE THE LIMITATIONS OF THE POINTS?
One of the limitations is that the points to consider were written as an expert consensus. This means they are based on the opinions of the group. However, all the points were drafted using published evidence. In the paper, the authors gave each item a score from 1 to 5 based on the quality of the evidence used to support it.

WHAT DO THE AUTHORS PLAN ON DOING WITH THIS INFORMATION?
The points will be shared with healthcare providers to help identify and support people with RMDs who are non-adherent. More research is needed in this area to test the ideas, and well-designed clinical studies would be helpful.

WHAT DOES THIS MEAN FOR ME?
If you have an RMD, your treatment should be tailored to your personal symptoms and circumstances. Decisions on medicines should be made between you and your doctor. It is a good idea to stay well-informed about your disease. This can help you stay motivated to keep on top of your treatment. It may also help you be more active and make lifestyle changes that could help.

If you have any concerns about your disease or its treatment, you should talk to your doctor.

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