

# Compliance in Rheumatoid Arthritis and the Role of Formal Patient Education

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**Objective:** This study was performed to determine the compliance with the basic treatments for rheumatoid arthritis (RA; medication, physical therapy, and ergonomic measures), to study psychological factors that influence compliance in light of the social learning theory, to learn whether patient education positively influences compliance and health, and to find an approach to patient education that improves compliance.

**Methods:** A MEDLINE search of the English language literature was performed.

**Results:** Few studies have dealt with compliance in RA patients; levels of adherence are generally low. According to the social learning theory, human function involves a continuous interaction between behavior, personal factors, and external environment. Self-efficacy is a personal factor that refers to the belief in one's capabilities and opportunities for being compliant with treatment advice. Patient education may improve ergonomic performance and compliance with physical exercise programs.

**Conclusions:** Compliance with medication was infrequently studied. Whether improved compliance leads to better health status could not be determined. Compliance with RA treatments are generally low. Systematic study of the effect of patient education on treatment and health is warranted. Self-efficacy enhancing techniques in patient education may improve compliance.

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**INDEX WORDS:** Rheumatoid arthritis; compliance; patient education.

IT IS NOW generally recognized that rheumatoid arthritis (RA) is not benign, but severe and progressive. The patients themselves see dependency, pain, disability, and affective disturbances as their main problems.<sup>1-3</sup> Their survival rate is lower than that of the general population,<sup>4-9</sup> and they are

six times more likely to suffer from severe limitation of activity.<sup>4,5,10</sup> Work disability rate among RA patients is 10 times and hospitalization rate twice the average for the general population.<sup>4,5,10</sup> In consequence, disease-related costs for the RA patient are high: these were assessed at more than \$40,600 over the course of a lifetime, on the basis of U.S. statistics for 1985.<sup>4</sup>

Basic treatment improves health and quality of life of RA patients. This consists of medication, physical exercises, and ergonomic measures. Frequently prescribed medications include nonsteroidal antiinflammatory drugs (NSAIDs) and disease modifying antirheumatic drugs (DMARDs). The former relieve pain and can improve joint function; the latter can suppress disease activity, improve function, and may retard joint destruction.<sup>11-13</sup> Physical exercises can improve muscle strength and general physical condition and may help to maintain or even extend range of motion.<sup>14-19</sup> The ergonomic measures prescribed for RA patients serve to conserve energy, protect joints, and im-

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prove daily functioning.<sup>20-22</sup> Although no studies have been performed to determine their relative contributions to health, medication is generally regarded as more important than physical exercises or ergonomic measures.

The success of treatment for RA depends as much on patient compliance as on treatment efficacy. Compliance, or adherence, has been defined as "the extent to which a person's behavior coincides with the medical or health advice."<sup>23</sup> It always refers to specific recommendations, such as taking a particular drug as prescribed.<sup>23-28</sup> We conducted a comprehensive search of the English medical literature, including a computerized search with MEDLINE, for articles dealing with compliance with treatment for RA and patient education. The results are presented and reviewed with a view to their relevance for clinical practice.

## COMPLIANCE

### *Medication*

Three studies have addressed adherence to NSAID treatment for RA (Table 1). Lee and Tan<sup>29</sup> interviewed 108 RA patients, who had been recruited by general practitioners for measuring compliance. Sixty-three percent stated that they took their antiinflammatory medication exactly as prescribed, 28% took it most of the time, 6% took it some of the time, and 2% did not take it. Ferguson and Bole<sup>30</sup> investigated the compliance of 40 RA patients randomly selected from among 312 patients treated at a university-based referral clinic. Thirty-two of these patients had been advised to take aspirin. The 25 (78%) who stated that they did so often were classified as compliant. Deyo et al<sup>31</sup> investigated compliance among 171 arthritis patients attending a rheumatology clinic. This population included 68 RA patients, 63 of whom were using NSAIDs. They used pharmacy refills for the number of pills to be consumed in a 1-month period; six refills were provided. For each patient, the number of monthly refills obtained was counted after 6 months. Compliance was measured and defined as the average percentage of intended monthly medication refills obtained. On average, the 11 patients using naproxen obtained 73% of the number of intended monthly refills; the 17 using ibuprofen, 61%; the three using indomethacin, 58%; and the 32 using aspirin, 69%.

Compliance with DMARD treatment for RA is dealt with in four studies (Table 1). In the study by

Deyo et al,<sup>31</sup> d-penicillamine was used by nine RA patients. Using the same definition of compliance and the same measurement method, a compliance of 84% was found after 6 months. Pullar et al<sup>32</sup> studied 26 RA patients who did not improve satisfactorily on high-dose d-penicillamine after 1 year or more to compare different measurement methods. They provided pills to which a low dose of phenobarbitone had been added as a pharmacological indicator and measured plasma concentrations after 4 weeks. The results were converted to a corresponding penicillamine dose. They also counted returned pills at the same visit, recorded the clinician's impressions of the compliance of individual patients, and interviewed the patients about their compliance. Compliance was defined as the consumption of at least 85% of the number of pills prescribed. According to the phenobarbitone measurements, 58% of the patients were compliant; according to the interviews, 96%; according to the pill counting procedure, 77%; and according to the clinician's impression, 42%. All noncompliers identified by the other methods were also identified by the phenobarbitone measurement.

Doyle et al<sup>33</sup> investigated the compliance of 59 consecutive RA outpatients using d-penicillamine for at least 2 months. To determine a cutoff point for compliance or noncompliance, they studied the urine, using an assay for a penicillamine metabolite in four compliant RA volunteers who were asked to stop treatment temporarily. After 1 day, urinary levels exceeded 100  $\mu\text{mol/L}$ , and after 5 days, the maximum level attained was 25  $\mu\text{mol/L}$ . Patients with levels of less than 25  $\mu\text{mol/L}$  were considered to be poorly compliant. The samples of 10 patients could not be analyzed. Thirty-nine percent of 49 patients were poorly compliant, whereas 61% were compliant. In our randomized study on the effect of patient education, which we conducted among 60 patients with active and recently developed RA, we determined the ratios of the numbers of sulfasalazine tablets consumed to the numbers prescribed.<sup>34</sup> The corresponding percentages were our measure for compliance. Six months into the study, average compliance among the 26 patients who did not participate in our educational program on sulfasalazine was 85%.

The populations studied were generally small. Differences in methodology make it difficult to compare results, let alone generalize them to clinical practice. If pharmacological indicators give the

**Table 1: Compliance With Basic Treatment for RA: NSAIDs, DMARDs, PHEX, and EM**

Treatment	Study	No. of Patients	Months*	Definition of Compliance†	Method of Measurement	Compliance (%)‡
NSAID	Lee and Tan (29)	108	?	Patient always takes medications	Interview	63 [68]
	Ferguson and Bole (30)	32	?	Patient often takes medications	Interview	78 [25]
	Deyo et al (31)	63	6	<i>Refills obtained/intended</i>	Pharmacological and medical records	<i>58, 61, 69, 73‡</i>
DMARD	Deyo et al (31)	9	6	<i>Refills obtained/intended</i>	Pharmacological and medical records	<i>84</i>
	Pullar et al (32)	26	1	Patient takes ≥85% medications	Pharmacological markers	58 [15]
	Doyle et al (33)	49	>2	100%—[Patient with low excretion]§	Metabolite in urine	61 [30]
	Brus et al (34)	26	6	<i>Pills used/pre-scribed</i>	Pill counting	<i>82</i>
PHEX	Treusch and Krusen (39)	218 [97]	3	Patient follows advice	Interview	65 [141]
	Parker and Bender (40)	56 [47]	>2	Patient follows advice	Interview	48 [27]
	Carpenter and Davis (41)	54	4	Patient follows methods + frequency exactly	Interview + expert opinion	55 [30]
	Ferguson and Bole (30)	35	?	Patient exercises >3×/week	Interview	43 [15]
EM¶	Nicholas et al (42)	36	?	Use while performing house-work	Interview	47 [17]
	Spoorenberg et al (43)	28	?	Use >2 hours/day	Interview	57 [16]

**Abbreviations:** RA, rheumatoid arthritis; NSAID, nonsteroidal antiinflammatory drug; DMARD, disease-modifying antirheumatic drug; PHEX, physical exercise; EM, ergonomic measures.

\*The period of treatment for which compliance was examined in months.

†Where compliance is expressed in % of patients, corresponding number of patients is given between brackets. When compliance is expressed in refills or pills, only % is given (*italics*).

‡These figures concern different NSAIDs studied by Deyo.

§Patients with a low urine level of a metabolite of the DMARD are considered poorly compliant. The others are considered compliant.

||In these studies the study population included patients with various rheumatic diseases. The number of RA patients is given between brackets.

¶Concerns the use of wrist splints to be worn during activity, which is the only ergonomic measure examined.

most reliable results, the work of Pullar et al<sup>32</sup> suggests that noncompliance is exaggerated in the physician's impression and underestimated by investigative interviews and, to a lesser extent, by pill counting procedures. There is, however, no ideal method of measuring compliance. Currently, electronic measurement methods are receiving much attention.<sup>35-38</sup> The above studies suggest that com-

pliance with NSAID and DMARD therapies is suboptimal.

#### *Physical Exercises*

Most studies dealing with compliance with prescribed physical exercises rely on interviews that provide quantitative information, such as how many exercises are performed or how often.

Treusch and Krusen<sup>39</sup> studied compliance with physical treatment programs, including physical exercises for various indications. The study population consisted of 218 patients, 97 of whom had RA. Ninety-three percent stated that they followed the prescribed treatments, but only 65% did so for at least 3 consecutive months after study initiation, which for purposes of this review is regarded as compliant.

Parker and Bender<sup>40</sup> studied the compliance of 56 patients, 47 with RA, with "home physical therapy," which includes physical exercise. Interviews with 38 of the patients took place 1 year or more after their therapies had been prescribed, the others between 2 months and 1 year after the initial prescriptions. Twenty-seven (48%) said that they were still following the prescribed programs.

Carpenter and Davis<sup>41</sup> studied 54 patients with RA. Theirs is the only study to consider the qualitative aspect of compliance. They defined compliance as exact conformity, both in method and in frequency, with the prescribed regimen. Compliance was determined 4 months after the prescriptions were made on the basis of patient interviews conducted by a visiting health professional, the opinion of this health professional, and a 30-day patient record of activity, including exercises. The authors do not describe the exact procedure that was followed to determine which patients were compliant. Thirty patients (55%) were classified as compliant and 24 as noncompliant.

The investigation by Ferguson and Bole<sup>30</sup> already mentioned included a cross-sectional study of 35 RA patients for whom exercises had been prescribed. They found that 20 patients performed these exercises three times a week or less. The other 15 patients (43%) were described as compliant. The time lapse between prescription and measurement was not given.

The results of these studies, summarized in Table 1, suggest that compliance with physical exercise therapies is generally suboptimal.

#### *Ergonomic Measures*

No studies in the available literature consider compliance with measures for energy conservation. The only two that deal with compliance with measures for joint protection concern the wearing of wrist splints. Nicholas et al<sup>42</sup> investigated the compliance of 36 RA patients advised to wear wrist splints when performing certain activities during

the day. Seventeen stated that they wore their splints when performing housework (47%) (Table 1). The investigators do not give the length of time that elapsed between prescription and investigation. Spoorenberg et al<sup>43</sup> interviewed 28 RA patients for whom splints had been prescribed. The splints were to be worn during activities that might cause undue wrist strain. Sixteen patients used the splint more than 2 hours a day (57%) (Table 1). In neither of these studies can the level of compliance be considered good.

#### PSYCHOLOGICAL ASPECTS OF COMPLIANCE

More than 200 factors have been studied in relation to compliance.<sup>44,45</sup> These include sociobehavioral features of patients, features of the diseases, therapeutic regimen, health care setting, and patient-practitioner interaction. We discuss here psychological factors that may lead patients to follow or reject therapeutic advice. We do so in the light of the social learning theory, which has received much attention the last 10 years in connection with education for arthritis patients.

#### *Patients' Beliefs*

That patients have their own ideas about the causes of RA and of flare-ups of RA activity was clearly shown by Kay and Panchak<sup>46</sup> through interviews with 100 RA patients. These ideas are not necessarily compatible with those of the patients' doctors. Whereas the physician looks for causal relationships, patients seek explanations for the general misfortune brought by disease.<sup>47,48</sup> In a survey of 32 patients with suspected RA, it was shown that patients develop systems of coping with the effects of joint disease on the basis of common sense and ideas offered by relatives, friends, or the laypress.<sup>49</sup> Treatment advice is more likely to be followed if it is compatible with the patient's system of coping.<sup>49</sup>

#### *Social Learning Theory*

The social learning theory was developed by Bandura<sup>50-52</sup> as a basis for understanding human behavior. He contends that human functioning involves a continuous interaction between behavior, personal factors, and external environment, a phenomenon that he calls "reciprocal determinism."<sup>50,51</sup> He postulates two personal factors as important determinants of behavior: outcome expectation and self-efficacy expectation. The former

refers to one's assessment of the chance that a certain behavior will have a beneficial effect, the latter to one's belief in one's capabilities and opportunities for executing this behavior.<sup>52</sup>

Outcome expectation with regard to specific treatments may be influenced by beliefs with regard to the causes of RA and its exacerbations. Those who believe, for example, that diet is an important cause of RA may have high outcome expectations with regard to diet modification. The effects and side effects of a treatment may influence outcome expectation and, subsequently, compliance. Capell et al<sup>53</sup> found that compliance with NSAID treatment is related to its effects and side effects. In a survey of 200 RA patients, Lorish et al<sup>54</sup> found that patients who decide not to take prescribed medication report side effects as the most important reason.

The significance of self-efficacy expectation for compliance was demonstrated by Beck et al.<sup>55</sup> By interviewing 63 RA patients, they found that patients' predictions concerning their compliance (self-efficacy expectation) with salicylate treatment was a good predictor of actual compliance as measured by salicylate assays.

Two important environmental factors are social support and health care setting. Carpenter and Davis<sup>41</sup> found that married patients complied more readily with recommended exercise regimens than did unmarried patients. In a study of 123 RA patients, Geertsen et al<sup>56</sup> found that patients who had a long wait to see the doctor or who were irritated at being kept waiting were less compliant. He did not measure the waiting times, however. Some support for the idea that the health care setting influences compliance is provided by the behavior of patients participating in multicenter research. A higher percentage of patients are willing to cooperate during the entire study in some health care centers than in others.<sup>57,58</sup> Feinberg<sup>45</sup> claims that physician-patient relationship is one of the most important factors influencing compliance. She suggests ways to improve compliance through interaction with the patient: Be approachable and establish a relaxed atmosphere; encourage patients to participate actively in their health care; strive for sharing of yours and patient's expectations of the disease, the treatment, etc.; and use appropriate pedagogical techniques.

## FORMAL PATIENT EDUCATION AND COMPLIANCE

Formal patient education comprises "all planned educational activities aimed at assisting patients in achieving voluntary health behavior changes."<sup>59</sup> We now consider formal patient education as an adjuvant to general practice in studies that evaluate compliance with treatment. We discuss relevant studies among RA patients and among arthritic patients.

### *Medication*

Kaye and Hammond<sup>60</sup> studied 48 RA patients, using a pretest-posttest design. The purposes of their program were to increase compliance with medication, physical exercise, joint protection, and energy conservation, to mitigate emotional problems, and to improve communication between the patient and his family and doctor. Forty-eight percent made "positive changes" in "taking medications," but measures of compliance were not included. We performed a randomized study, cited above, among 60 RA patients with recently developed active disease.<sup>34</sup> The effect of patient education on compliance with sulfasalazine, physical exercise, and ergonomic measures was assessed. We defined compliance as the ratio of the number of tablets consumed to the number prescribed. Using a pill counting procedure, we found the average compliance to be above 80% in the experimental group and in the control group, with no significant differences between groups.

### *Physical Exercise*

Potts and Brandt<sup>61</sup> performed a controlled trial among 38 RA patients to determine, among other things, whether their program of patient education would improve compliance with exercise therapy. The experimental group was provided with information on RA and its treatment. Although the knowledge of these patients increased, there was no change in compliance (Table 2).

Increased compliance with exercise therapy was found by Lorig et al,<sup>62</sup> who investigated the effect of patient education in a randomized study involving 190 arthritis patients (11% with RA). Their program included physical exercise, relaxation techniques, joint protection, interaction with physicians, and methods of solving disease-related problems.

Lindroth et al<sup>63,64</sup> conducted a controlled study

**Table 2: Effect of Patient Education on Compliance With Physical Exercise**

Study	No. of patients	Design	Follow-up (mo)	Effect
Potts and Brandt (61)	38	Controlled	1	None
Lorig et al (62)	190 [20]*	Randomized	4	Increase
Lindroth et al (63)	200 [135]*	Controlled	12	Increase†
Taal et al (65)	75	Randomized	14	Increase
Brus et al (34)	60	Randomized	6	Increase

\*In these studies patients with various rheumatic diseases were included. The number of rheumatoid arthritis patients is given between brackets.

†In this study, compliance with physical exercise and with recommendations for simplifying work and joint protection were expressed as a single variable.

of the effect of patient education on 200 arthritis patients (67% with RA). Their program was intended to teach factual knowledge, develop skills, and help in coping with chronic disease. Compliance with physical exercise and with recommendations for simplifying work and joint protection was expressed as a single variable, and it is not entirely clear how its value was determined. One year after the educational program ended, the composite variable for compliance showed overall improvement.

In a controlled randomized study involving 75 RA patients, Taal et al<sup>65</sup> found that patients who followed a modified version of Lorig's educational program performed prescribed physical exercises more frequently after 6 weeks than they had at the beginning of the program. This effect was still in evidence after 4 and, to a lesser extent, after 14 months (Table 2). In our study, we also found that education improved compliance with exercise therapy.<sup>34</sup>

#### *Ergonomic Measures*

Gerber and Furst<sup>66,67</sup> studied the effects of patient education on energy conservation in 28 RA patients. The experimental group followed the program 1.5 hours a week for 6 weeks. Measurements were performed after 3 months. All subjects kept diaries in which they registered their activities over 2 days divided into half-hour segments. More patients in the experimental group than in the control group increased the number of breaks per hour spent physically active. More patients in the experimental group increased the amount of time spent in physical activity. However, the differences between the groups in these respects were not significant.

Kaye and Hammond,<sup>60</sup> in an uncontrolled study of 48 RA patients, found an increase in self-

reported application of measures for joint protection and energy conservation in more than half of their study population as a result of patient education. In the previously mentioned investigation by Lindroth et al,<sup>63,64</sup> the experimental group reported an increase in the application of measures for work simplification and joint protection and the performance of physical exercise after 1 year.<sup>63</sup> After 5 years, these effects were no longer detectable.<sup>64</sup>

Hammond<sup>68</sup> performed an uncontrolled study on the effect of patient education on compliance with joint protection in 10 RA patients. No change in a test for ergonomic performance was noted after 3 months. Nevertheless, all patients stated that they paid more attention to joint care as a result of the program. The author suggested that attitudes may have changed and that longer follow-up might be necessary to discern clear effects on behavior. The disparity between change in attitude and change in behavior might, however, be a shortcoming of the assessment procedure, which had not been externally validated.

Barry et al<sup>69</sup> performed an uncontrolled study of the effect of ergonomic instruction on 55 RA patients. Patients had a better understanding of ergonomic measures 3 and 6 months after instruction began. Whether ergonomic performance improved remains uncertain. In our study, we found that patients who followed the educational program scored higher than controls on a test of ergonomic performance 3 months after the program started.<sup>34,70</sup> However, the test was not externally validated.

Nordenskiöld<sup>22</sup> performed an uncontrolled study on the effect of a joint protection course on 53 RA patients. The patients reported trying a total of 663 devices, 91% of which were still in use 0.5 to 1.5 years after the course.

The preceding indicates that patient education might improve ergonomic performance.

### *Improving Compliance by Patient Education and the Effects on Health*

The effectiveness of treatments may be expected to improve with increasing levels of compliance. In addition, psychological factors appear to contribute to the effect of patient education on health in patients suffering from RA or other diseases.<sup>71-73</sup>

The effects of patient education on health status were studied by Lorig in arthritis patients and by Taal in RA. Both investigators based their approaches to patient education on Bandura's social learning theory. The teaching strategies used were aimed at enhancing self-efficacy expectation. In their original study, described above, Lorig et al<sup>62</sup> found that after the course participants experienced diminished pain. When the study population was increased from 190 to 707, they also found a trend toward diminished disability and depression.<sup>72</sup> Taal et al<sup>65</sup> showed that group training had a positive effect on functional ability in RA patients. Lindroth et al<sup>63,64</sup> found improvement of functional ability in arthritic patients. It should be noted that improvement of compliance with therapies involving medication, although an important part of basic treatment, was not a specific aim of the courses employed in these studies. The goals of their education programs only partly concerned the improvement of compliance with basic treatment. Among the skills taught were relaxation exercises and communication techniques.

We did not find effects of formal patient education on health in RA patients.<sup>34</sup> The high compliance with sulfasalazine in both groups led to improvement in health status, without differences between groups.

Gerber and Furst<sup>66,67</sup> did not find health effects after their instructions for energy conservation in RA. Their study population, however, was small. Nordenskiöld et al<sup>22</sup> studied the effect of ergonomic instructions in RA patients and found that pain decreased while more devices were used.

#### APPROACH IN FORMAL PATIENT EDUCATION

No systematic study has compared the effects of different strategies and techniques in patient education.<sup>74</sup> Factors that might reasonably be expected to influence compliance include the role of partners, patients' beliefs about the cause of RA and its flare-ups, outcome expectation with regard to specific treatments, and self-efficacy expectation. The last-mentioned can be enhanced by performance

accomplishments, vicarious experience, persuasive communication, and the correction of false interpretations of physiological state. To implement the first of these, the goals set in patient education programs must be attainable to optimize the chance for success. Patients should have the skills that are needed before treatment advice can be adequately followed. By example, they should be able to execute recommended physical exercises properly. Vicarious experience, or modeling, is often used in group education, where other patients can act as models. Prudence is called for in the use of persuasion, because unrealistically high self-efficacy expectations can lead to failure. Correcting false interpretations of the patient's physiological state is important because people tend to interpret physiological signals, such as the pain of active arthritis, as indicators of personal inefficacy in managing or coping with their disease.<sup>77-77</sup>

The foregoing leads to the following recommendations concerning patient education: (1) Organize patients into groups and involve partners. (2) Learn what people believe about RA and how they interpret their symptoms. If necessary, correct beliefs and reinterpret symptoms. (3) Determine what effects and problems people expect from treatment. Correct their ideas when necessary and discuss expected problems. (4) Teach the skills required for successful execution of treatment (ie, the way physical exercise should be performed etc). (5) Encourage patients to plan their treatment and discuss and redefine unrealistic plans. (6) Encourage patients to make contracts with themselves to put their plans into practice. (7) Provide feedback.

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