Importance of Shared Treatment Goal Discussions in Rheumatoid Arthritis—A Cross-Sectional Survey: Patients Report Providers Seldom Discuss Treatment Goals and Outcomes Improve When Goals Are Discussed

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Objective. Treat-to-target (T2T) and shared decision-making are valued features of current guidelines for rheumatoid arthritis (RA) management. Although T2T has demonstrated value for improving RA outcomes, implementation remains inconsistent and lacks standardization and procedures for including patient input. We sought to better understand the impact of shared decisions on T2T and how treatment goal discussions between patients and providers impact RA treatment improvement and satisfaction.

Methods. An anonymous, web-based questionnaire was presented to United States residents aged 18 years or older with a self-reported diagnosis of RA by a medical professional with 28 questions regarding socio-demographics, RA disease activity (DA), diagnosis, treatments, outcomes, and goals. Analyses included descriptive statistics with χ² and rank sum tests for comparisons.

Results. The questionnaire was completed by 907 people (mean age of 58 years; mean 11 years since diagnosis; 90% female). The majority (571; 63%) did not discuss RA treatment goals with providers. Patients engaging in treatment goal discussions with their providers were three times more likely to be satisfied with their treatment plans. Patients discussing treatment goals with their providers were more likely to have improved DA levels and 68% more likely to reach remission.

Conclusion. A majority of patients with RA report having no treatment goal discussion with their providers; however, these discussions are associated with greater DA improvement and treatment satisfaction. Further research should seek understanding of how shared treatment goal discussions relate to successful RA management and explore the development of practical tools to implement them in regular clinic practice as part of a T2T regimen.

INTRODUCTION

Rheumatoid arthritis (RA) is an autoimmune disease generating systemic inflammation, leading to increased disability, morbidity, and mortality because of its effects on several bodily systems. Hallmark symptoms include painful inflammation and destruction of joints and connective tissues, fatigue, and low-grade fever. Over time, the disease process impairs health-related quality of life by damaging joints and organs (1). Although RA is still an incurable disease, numerous treatments developed in recent decades reduce disease activity (DA) and slow progression of the disease; these are referred to as disease modifying antirheumatic drugs (DMARDs) and include both biologic DMARDs and targeted synthetic DMARDs. Formerly, RA was treated with a pyramid-type approach, beginning with less hazardous, less effective anti-inflammatory medications and gradually advancing to more aggressive treatments as the disease progressed. In contrast, over the past two decades, guidelines...
have emphasized the employment of DMARD monotherapy early in rheumatology care. Current treatment paradigms are also more aggressive with earlier escalation to all types of DMARDs.

However, DMARDs are more effective in some patients with RA than others; clinical study results generally follow a rule of thirds: roughly one-third of participants have little or no response, one-third have a partial response, and one-third have a good response (2–4). A majority of people with RA still experience disease symptoms that interfere with daily life (5,6). Evidence shows that DMARD response levels improve under certain conditions, including early treatment and “tight control” of DA (7–12). In recent years, RA treatment guidelines and recommendations have been systematically developed with the intent to improve outcomes for people with RA on the basis of clinical studies that have supported this approach (8,11,13,14). Two significant recurring aspects of these recommendations are “treat to target” (T2T) and shared decision-making (SDM).

SDM in RA care has been shown to be less than optimal although it is almost universally advocated because of its potential impact on outcomes or patient satisfaction. SDM is associated with longer visit duration (15) and has multiple other logistical barriers to its implementation in RA care (16). Several SDM tools have been developed for use in RA management, but none has been widely adopted.

The T2T approach employs “tight control” by defining a treatment goal or “target” and modifying the DMARD therapy if the target is not reached. Two fundamental features of this process are setting the target or treatment goal and regularly measuring DA, preferably with a composite measure (8,11,17–19). Although it is almost universally agreed that remission or low DA (LDA) is the optimal goal for RA treatment, there is no gold standard for identifying RA remission or LDA (10,17,20,21). Therefore each treatment decision is just that—an individual decision based, in

| Characteristics                          | Results  |
|------------------------------------------|----------|
| Current age, mean (SD), yr              | 57.9 (10.8) |
| Sex, n (%)                               |          |
| Female                                   | 815 (90) |
| Male                                     | 91 (10)  |
| Age at diagnosis, yr Mean (SD)           | 46.9 (12.9) |
| Median                                   | 48.0     |
| Time since diagnosis, Mean (SD), yr      | 11.1 (10.1) |
| Time from diagnosis to treatment, Mean (SD), yr | 0.9 (3.8) |
| How satisfied are you with your RA treatment plan with your healthcare provider? n (%) | |
| Very dissatisfied                        | 61 (7)   |
| Dissatisfied                             | 163 (18) |
| I don't have an RA treatment plan        | 35 (4)   |
| Satisfied                                | 433 (48) |
| Very satisfied                           | 215 (24) |

Participants were asked questions related to demographics, RA disease activity and RA treatment. Standard deviations or frequencies are shown where applicable. Abbreviation: RA, rheumatoid arthritis.
part, on a patient’s RA symptoms and complications, personal preferences, and possible medication side effects.

There are major difficulties in the treatment of RA, including heterogeneity of the disease, medications that are only partially effective, and delayed diagnosis due to misperceptions over the earliest disease symptoms (6,8,11,22,23). Several reports indicate low levels of implementation of key aspects of T2T in actual rheumatology practices (18,19,24–29). These topics have been a principal focus of discussion for our study, the aim of which was to identify whether patients with RA have discussions with their rheumatology provider about setting treatment goals and the extent to which such discussions may impact treatment outcomes or patient satisfaction with rheumatology care.

PATIENTS AND METHODS

Study design and data collection. This study was part of an ongoing collaborative effort between an academic rheumatology center, Mayo Clinic rheumatology, Rochester, and a nonprofit patient advocacy organization, the Rheumatoid Patient Foundation 501c3 (RPF). The group consists of clinicians, investigators, patients, and first-degree relatives of patients who have been involved in treating RA or investigating RA management or both for several years. The full group accepted survey questions that were developed by the patient advocate team in the following manner: KO wrote the first draft with input from KM. All RPF board members participated in two rounds of evaluating and revising the survey questions, with significant input from PS, who is trained in survey methodology. Board members then piloted the survey using links sent via email.

The study plan and content were evaluated by the Mayo Clinic Institutional Review Board and deemed exempt. The final questions were then uploaded to the Wufoo website (part of Survey Monkey) by DS. Between May 23 and May 31, 2019, the survey was offered on their secure online survey platform that prevents multiple entries. Neither the survey website nor our group collected any identifying information from the study participants.

Study participants. Participants were recruited via online links by the RPF and its founder (KO) using their respective email lists and website channels dedicated to topics related to RA. The total population that could be reached with links to the survey was 127,400, but the actual number was potentially smaller because of the potential for overlapping membership on the two separate websites and their social profiles that were included in this study. For example, people may have been listed on a site’s email list and followed a site’s Facebook page as well.

Before beginning the survey, patients were provided information regarding the study and its purpose and contact information in case of questions. Patients were required to agree to participate in the study, affirm a medical diagnosis of RA, and confirm being aged 18 years or older and living in the United States to be included in the study. When asked the number of DMARDs they had been prescribed for disease treatment, only seven responded “0” (<1%).

Patients answered a total of 28 multiple choice and open-ended questions regarding their demographics, disease history, and responses to treatment for RA (Table 1). Patients were also asked about their experiences and preferences in setting RA treatment goals. We have published some of these data at previous American College of Rheumatology (ACR) meetings (30–33). Several other survey questions were examined by whether patients responded “yes” or “no” to “Did your healthcare provider ask you what your goals were for RA treatment?” (Figures 1 and 2 and Tables 2 and 3.)

Statistical analyses. The 907 responses were downloaded to a Microsoft Excel spreadsheet. Descriptive statistics (means, percentages, etc) were used to summarize the data. Comparisons between groups were performed using χ² and rank sum tests. Logistic regression models were used to determine odds ratios (ORs) with 95% confidence intervals (CIs) to quantify effect sizes. Analyses were performed using SAS version 9.4 (SAS Institute).

Figure 1. Treatment goal discussions and DA improvement rates. Participants were asked, “Did your healthcare provider ask what your goals were for RA treatment?” and “Thinking of all your symptoms, what was the highest percentage of symptom improvement or relief that you’ve had from disease treatment?” Percentage of highest level of DA improvement is shown for those responding “No” or “Yes.” DA, disease activity; RA, rheumatoid arthritis.
The population consisted of 907 residents of the United States (≥18 years of age); 815 (90%) were female and 91 (10%) were male. The mean (SD) age of participating patients was 57.9 (10.8) years, and the mean (SD) duration since RA diagnosis was 11.1 (10.1) years. Reported racial heritage was mixed, with 89% reporting “white” (Table 1). A majority responded “no” (571; 63%) when asked whether they had definite discussions about treatment goals with their providers as part of their rheumatology care (“Did your healthcare provider ask you what your goals were for RA treatment?”). In examining several other survey responses, patients who responded “yes” or “no” were considered as two separate groups.

Five percent (n = 49) of patients said that their RA was in “remission,” 22% (n = 196) described their current level of DA as “mild,” 54% (n = 486) described it as “moderate,” and 19% (n = 176) described it as “severe.” Patients who had a “shared treatment goal discussion,” a definite conversation with their providers about RA treatment goals, were somewhat more likely to say they were in mild DA or remission (OR: 1.31; 95% CI: 0.97-1.76) as opposed to moderate to high DA. Remarkably, patients having treatment goal discussions with their providers were 68% more likely to report a state of remission (OR: 1.68; 95% CI: 0.94-2.99).

Shared treatment goal discussions associated with higher levels of DA improvement. In estimating their “highest level of DA improvement,” patients selected “less than 20% improvement,” “about 20% improvement,” “about 50% improvement,” “about 70% improvement,” or “greater than or equal to 90% improvement.” Those whose providers discussed goals with them were more likely to report greater levels of DA improvement (Figure 1). The higher the level of DA improvement, the more likely the patient was to have had treatment goal discussions with the provider (Table 2).

The relationship between the occurrence of shared treatment goal discussions and levels of DA improvement could be seen in both low and high ends of the DA range; in those who shared treatment goal discussions with their provider (“yes”), fewer had DA improvement levels of 20% or less (yes, 23%; no, 37%). They were also more likely to have DA improvement of 70% or more (OR: 1.77; 95% CI: 1.34-2.33) (Table 2). Patients answering “yes” were 80% more likely to reach very high levels of DA improvement (≥90%) (OR: 1.80; 95% CI: 1.26-2.58). The “yes” group was also 94% more likely to have DA improvement of 20% or more (OR: 1.94; 95% CI: 1.43-2.64), with only 6% nonresponders (<20% improvement).

Having treatment goal discussions associated with higher levels of patient satisfaction. Patients with treatment goal discussions (“yes”) were 3.37 (95% CI: 2.33-4.86) times more likely to say they are satisfied or very satisfied (86%) when asked “How satisfied are you with your RA treatment plan with your healthcare provider?” A majority of patients who did not discuss treatment goals (“no”) were also satisfied (63%), but this was by a much smaller margin because 32% were dissatisfied or very dissatisfied (Figure 2). Only 35 people (6%) said they had no RA treatment plan at all (“I don’t have an RA treatment plan”). Five people (1%) said they had discussed treatment goals with the provider (“yes”) but still did not have an RA treatment plan.
Whether or not goals are discussed, people with RA strongly favor the use of goal-setting tools. Although both groups showed distinct patterns in answer to several questions, they were indistinguishable when asked about preference in using “shared goal-setting tools” in RA treatment. Whether or not they had previously participated in goal-setting discussions with their provider, people responded favorably to the notion of such a tool to aid in setting treatment goals together. A total of 78% of people in the “no” group answered likely or very likely to “How likely would you be to use materials that could help you and your provider work together to set treatment goals?” and 80% of the “yes” group answered the same (Table 3). A high percentage of people at every level of DA improvement were also likely or very likely to use shared RA goal-setting tools (<20% DA improvement, 77%; 20% DA improvement, 78%; 50% DA improvement, 79%; 70% DA improvement, 81%; and ≥90% DA improvement, 79%) (Figure 3).

DISCUSSION

The ACR and the European League Against Rheumatism (EULAR) have adopted explicit recommendations in order to assist rheumatologists in providing optimal care for patients with RA. Recommendations of both the ACR and the EULAR emphasize the “shared decision” between a patient and a rheumatology professional in treatment related decisions (8,11). Both entities also highlight the value of treating RA early and setting a specified treatment goal or “target.” The concepts of SDM and T2T have become part of the standard of care for RA. The ACR revised RA treatment guidelines in 2021, again affirming that “individual treatment decisions should be made through a SDM process based on patients’ values, goals, preferences, and comorbidities” (34). The guidelines reiterate the important role of SDM (“Treatment decisions should follow a shared decision-making process”) as well as the importance of treating to target by regularly evaluating DA and adjusting DMARDs accordingly. New recommendations for possible drug tapering also emphasize consideration of patient preferences.

However, despite these guidelines and substantial expansion of the number of medications available to treat the disease, most people with RA do not achieve optimal levels of improvement. A survey of 586 people with RA in nine European countries indicated that a majority reported “frustration that they could no longer perform their premorbid activities” (35). In fact, although they were, in theory, receiving the current standard of care, a majority “considered their lives to be controlled by RA.” Population-based estimates of RA treatment patterns suggest that T2T strategies are frequently not implemented, with regard to either early DMARD administration or escalation of care for insufficient DA improvement (24,25,28,36). Medicare management records demonstrate that 35% to 60% of patients with at least two diagnostic codes for RA have no record of filling DMARD prescriptions (27).

Although treating to target is considered optimum care, an examination of the literature reveals several challenges associated with implementing T2T or setting treatment target goals (37). The results of our survey shed new light on some of those problems and raise important questions for others. One review of 15 years of T2T trials found that the evidence for “long-term improved outcomes is less robust” for RA than for other diseases (27). Another review of the evidence used to create the RA treatment guidelines
found high-quality evidence to be “sparse” (20). However, numerous clinical trials have shown greater clinical improvement when patients with RA are treated with precisely set targets and rigorously measured (7,9,10). In our study, the majority (57%) of those who had no treatment plan at all (n = 35) had DA improvement of 20% or less, whereas only 32% of all patients surveyed had DA improvement levels that low.

RA treatment guidelines emphasize SDM as part of a T2T regime (8,11). Well-informed patients can enjoy better outcomes (21), and patient involvement in setting goals makes them more likely to be achieved (38). Even patients with terminal cancer have less depression and longer survival when they are involved in helping to manage their own palliative care plans (39). However, people with RA often have difficulty raising concerns with their physicians (1,37). A majority of our survey respondents did not share in treatment plan decisions; although 63% recalled having no specific discussion about a treatment goal with their provider, 94% did have a treatment plan (only 6% said they had no treatment plan at all). It could be inferred that a majority of patients assumed that their provider had his own plan although it had not been discussed together. SDM, as part of a T2T strategy, seems to be the difference; we found that the higher the level of DA improvement, the more likely patients were to have shared treatment goal discussions with their providers. Approximately 80% of patients with RA strongly favor using tools to facilitate shared treatment goal decisions with rheumatology providers, and professional guidelines strongly recommend such shared treatment decisions.

Some patients with RA have complex medical concerns with bearing on DMARD options or other treatment concerns that make SDM more challenging and, conceivably, more valuable. Discussing or setting treatment goals together may not eliminate discordance between patient and provider, but having a discussion about the individual treatment goals allows both to be cognizant of any tensions that may exist. In considering setting treatment targets together, shared treatment goal discussions may exploit advantages of both T2T and SDM. However, various practical problems may hinder implementation of shared T2T decisions.

First, it has often been noted that misclassification of remission or LDA is likely with DA assessment tools originally intended for use in research settings. For individual patients with RA, the monitoring of RA disease activity in daily clinical practice demands a personalized approach; clinical decision making based only on an aggregate value of a composite index such as DAS28 is insufficient” (17). Jacobs points out that the DAS28 disease activity score was not validated for use in individual patients with RA but “for evaluations at a group level, i.e. for measuring effects in clinical trials” (17). He outlines specific respects in which using the DAS28 “has serious drawbacks, especially when used for applying the treat to target principle in an individual RA patient.” The DAS28, Simple Disease Activity Index, and Clinical Disease Activity Index tools also assess only 28 joints, sparing the feet, ankles, hips, and cervical spine. This underestimates actual DA and joint damage, especially in 25% of patients whose early RA disease predominantly affects the feet (40). According to Mease, treatments are often determined without reference to appropriate targets simply because these complex instruments are “unsuitable for busy rheumatology clinics” (21).

Second, in a behavioral intervention trial to incorporate a T2T approach, Harrold et al found difficulties with convincing patients of the “virtues of treat-to-target care” (41).

Finally, even the panel creating the EULAR guidelines acknowledged that the sheer amount of information generated by numerous clinical trials of several new drugs “does not always allow one to decide easily and conclusively which path to follow when initiating or changing therapeutic strategies in patients with RA” and can thus be overwhelming to both patients and rheumatologists (8).

We only surveyed patients with RA about their experiences in rheumatology care, but several studies have surveyed rheumatology professionals and explored the low levels of implementation of the guidelines for the treatment of RA, even when professionals consent to said guidelines (19,24,26). Lesuis et al found that adherence “varied among rheumatologists, and several rheumatologist and patient-related determinants (rheumatologists’ scientific education status, patient sex, number of DMARD options, presence of erosions, comorbidity, RF/aCCP positivity, type of patient) were found to be related to rheumatologists’ guideline adherence” (26). The IRIS study (International Recommendation Implementation Study) of 132 rheumatology practices in 14 countries found discrepancies between reporting agreement with the RA recommendations and actual performance in clinical practice (19). Inconsistencies with the application of the guidelines in both initiation of DMARD treatment and T2T (19,24,26,29) could suggest that there is a lack of practical tools for implementation of T2T and SDM in daily practice. Further research should investigate tools for shared decisions in T2T with better practical application to actual clinical practice.

People with RA can also have differing perceptions of the disease than their providers and subsequently make differing treatment decisions (1,28,37,42). In particular, patients have difficulty discussing the impact RA has on their ability to function in their lives (1,35). Nonetheless, people with RA rate physical function first of 58 items that influence decision-making about RA treatments, whereas rheumatologists prefer swelling as the primary factor (28). Patient-reported outcome (PRO) measures demonstrate another important difference in patient perceptions of RA disease activity; people who have made behavioral adaptations to manage their disease may not reflect changes in their PRO DA scores (27,43). This can make them less willing to escalate treatment. Gibofsky et al likewise describe “important disconnects” between patients and doctors that may impact decision-making in RA management (1). The impact of these differing perceptions and communications should be considered as tools to facilitate the development of shared treatment goal discussions.
Effective communication and participation in treatment decisions have been shown to be priorities for people with RA and significantly contribute to satisfaction with treatment experience (1,44). Similarly, our data show that people are more than three times more likely to be satisfied or very satisfied with their treatment experience if they have treatment goal discussions with their providers. However, treatment satisfaction does not necessarily associate with DA improvement level, as Wolfe and Michaud explain, “there is substantial discrepancy between RA patients’ declared satisfaction with their treatment and measured disease activity and functional status. Most patients are satisfied with their therapy, even many with abnormal scores” (45). Likewise, a majority of patients we surveyed expressed satisfaction with their rheumatology care; 83% of those reporting remission or mild DA were satisfied or very satisfied, as were 72% of those reporting moderate DA, and even 53% of those reporting severe DA were satisfied or very satisfied. Patient satisfaction in our study more closely related to having had treatment goal discussions with the rheumatology provider than it related to a patient's DA level, which is similar to Brekke’s result: “Levels of involvement and global satisfaction with health care were significantly related” (46).

This study has some limitations. First, being a patient-based survey, our findings were based on patient self-reports, which rely on patients’ accurate recall of discussions that occurred as part of their RA management. Nevertheless, understanding and recalling specific conversations about treatment goal-setting may be an indicator of effective SDM and a high level of patient participation. DA levels were also reported by patients directly, relying on both their understanding of customary categories of RA disease activity (“remission (no symptoms), mild, moderate, and severe”) and their recall of either their medical records or of conversations with their providers. Self-reports of patients with RA related to DA and its management have been considered for many years and have been found valid for estimating flares or joint counts that correlate with provider measures (10,47–49). Data on DA are regularly gathered directly from patients for large data banks and registries (50,51).

Third, as a cross-sectional study, even strong associations cannot be assumed to imply causal relationships between data points. As such, our conclusions are only valid to the degree that our patient sample is representative of the entire population of patients with RA. Although this remains a limitation because our study is vulnerable to selection bias, our methods and demographics appear to be similar to those of other published studies based on online surveys (1,5,36,37,45).

Our study also has several strengths, in particular its large sample size (>900 patients with RA). The sample is also representative of the wide range of DA levels and treatment responses. This is the first study to investigate the degree to which T2T is used in regular clinical practice by asking patients about shared treatment goal discussions. This study demonstrates that SDM and T2T—two crucial aspects of current RA treatment guidelines—are fundamentally connected. Patient partnership in treatment decisions appears to be a key aspect of T2T success, demonstrated by the overwhelming relationship between shared treatment goal discussions and patient satisfaction (more than threefold). Another strength of the present study is that it is the first to examine the relationship between shared treatment goal discussions and DA improvement levels; the data show they are clearly linked.

This study is part of a long-term collaborative effort to consider experiences of both patients and clinicians and to incorporate them in exploring ways to improve outcomes in patients with RA. An additional strength of this study is that our group’s participatory research process included patients, clinicians, and other investigators in all aspects of its conception, design, and implementation. This could potentially increase its relevance to all stakeholders, both patients and providers.

Despite their limitations, our data provide compelling insights that establish a need for further investigation of the relationship between shared treatment goal discussions and DA improvement in RA. Both the usefulness of T2T in RA outcomes and the value of SDM are well established. However, recommendations and evidence are lacking on how the two should be implemented and integrated. Future studies should identify aspects of shared treatment goal discussions that are most practical for regular clinical care and have the greatest impact on DA improvement levels. The extremely high patient satisfaction levels of those in our study who engaged in shared treatment goal discussions should further encourage such research. Overall, our data demonstrate the need to explore the development of tools to incorporate shared treatment goal discussions in regular clinical care for RA.

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AUTHOR CONTRIBUTIONS

All authors were involved in drafting the article or revising it critically for important intellectual content, and all authors approved the final version to be published. Dr. O’Neill had full access to all of the data in the study and takes responsibility for the integrity of the data and the accuracy of the data analysis.

Study conception and design. O’Neill, Marks, Sinicrope, Symons, Myasoedova, Davis.

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