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Preference phenotypes can be used to support shared decision-making at point-of-care for patients with rheumatoid arthritis: A proof of concept study

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Abstract

Objective: In this proof-of-concept study, we sought to evaluate whether a value clarification tool enabling patients to view a set of rheumatoid arthritis (RA) treatment preference phenotypes could be used to support shared decision-making (SDM) at the point-of-care.

Methods: We conducted a pre-post test study. All English-speaking RA patients presenting to their scheduled outpatient visits were asked to participate. Visits for patients with active RA were transcribed. SDM components were measured using a quantitative coding scheme based on an established model of SDM.

Results: Forty-six visits were included in the pre-test and 40 in the post-test phase. Providers offered more DMARDs (two or more) in the post-test visits (60%) compared to the pre-test visits (47.8%). Overall, more patients vocalized their values and/or preferences in the post-test visits compared to the pre-test visits for treatment escalation decisions including choice of one new DMARD (90.9% versus 56.3%), two or more new DMARDs (95.8% versus 86.4%), as well as prednisone (87.5% versus 66.7%). Providers were also more likely to base their recommendations on patients' values and/or preferences in the post-test (100% of six visits) than pre-test (64.3% of 14 visits) phase during visits in which a recommendation was made. The average (SD) length of the visit was 29.9 (11.6) minutes and 25.1 (10.7) minutes in the pre- and post-test phases respectively.

Conclusion: This study provides an early indication that a value clarification tool allowing patients to consider a set of preference phenotypes can support SDM at the point-of-care without extending visit time.

Prompt and aggressive treatment of early rheumatoid arthritis (RA) (1) and tight control of established RA (2) improve both short- and long-term outcomes, thereby decreasing overall morbidity and disability. Current American College of Rheumatology guidelines recommend that clinicians adopt a “treat-to-target” (T2T) strategy with the goal of achieving low disease

activity or clinical remission.(3) While escalation is recommended for the vast majority of patients who are not at target, T2T recommendations do not explicitly endorse any specific intervention. Thus, treatment plans should be individualized based on mutual patient-clinician consideration of patient priorities using shared decision-making (SDM); a process in which well-informed patients deliberate with providers about choices and arrive at a decision concordant with patients' stated informed values and/or preferences.(4)

Although no single definition for SDM has been established, essential features of all models include information exchange followed by patient-physician deliberation.(5) Elwyn et al.(4) described a practical three-step model for SDM: 1) create awareness that a choice exists (i.e., "choice talk"), 2) provide decision support through discussion of options, including pros and cons (i.e., "option talk"), and 3) discuss patient values and/or preferences and arrive at a shared decision (i.e., "decision talk"). SDM improves patient-physician communication, increases patient satisfaction, and enables patients to feel more empowered to make difficult decisions, which can result in more favorable health outcomes.(6,7) Still, patient preferences for participating in decision-making vary, with some preferring to defer all responsibility to their physician (8) and others viewing themselves as the primary decision makers.(9) However, in the vast majority of studies, most patients prefer a collaborative approach, wherein they are fully informed of their options, given the opportunity to state their values and goals, and arrive at a decision collaboratively with their physician.(10)

Decision aids are widely recommended as a means to facilitate SDM. Patients randomized to decision aids are better informed, more certain of their values and more likely to play an active role in decision-making compared to controls.(11) Yet, despite the widespread endorsement of the SDM model, decision aids have not been effectively integrated into the healthcare system and patients are rarely effectively engaged in the decision-making process. To improve uptake, some decision aids have been designed to be used by patients prior to the clinical encounter.(12) This approach improves patient knowledge, but has not been shown to influence choice behaviors for patients with chronic diseases such as RA. Thus, to date, no decision aids have been developed to improve SDM for T2T decisions at the point-of-care. In this proof-of-concept study, we sought to evaluate whether a value clarification tool enabling patients to view a set of RA preference phenotypes derived from a large stated preference study could be used to support SDM at the point-of-care.

METHODS

Development of the Value Clarification Tool

We generated a set of five preference phenotypes by applying latent class analysis to stated preferences collected using a conjoint analysis survey in a large group of RA patients: members of the largest group (38.4%) were affected most by the cost of medications, members of the second largest group (25.8%) were concerned about the risk of bothersome side effects, members of the third largest group (18%) were most impacted by onset of action and risk of serious infections. The two smallest groups were most concerned about the risk of very rare side effects (11.2%) and the route of administration (6.6%) (13). Generation of the phenotypes is discussed elsewhere.(13) We subsequently (LF and patient co-investigator CW) developed an initial prototype of the value clarification tool to illustrate

the set of preferences using lay terminology and familiar concepts (e.g., star rating system). The tool, in a paper brochure form, describes the impact of seven characteristics on patient preferences: onset of action, route of administration, common side effects that affect quality of life, risk of serious infections, very rare side effects, time on the market, and affordability. Values for the seven characteristics were displayed in three tiers: “Our TOP priority is to:” (five stars), “Other things that influence our decision:” (three stars), “We pay little attention to:” (1/2 a star) for each of the five phenotypes. A list of recommendations to consider based on values is also provided. The tool was modified based on repeated rounds of feedback from patients with RA and designed with the help of the Yale Media Department. The final version is provided in the Appendix.

Study Design and Procedures

We conducted a pre-post test study. The pre- and post-test phases were separated by two weeks. Clinicians were introduced to the value clarification tool one week prior to the post-test phase. They were briefed on how the tool was developed, but were not given specific instructions on how to use it in clinic. Procedures were identical in both phases, except for the availability of the value clarification tool in the post-test phase.

Although the tool was developed for patients eligible for triple therapy or a biologic disease-modifying anti-rheumatic drug (bDMARD), all English-speaking RA patients who presented to their scheduled outpatient visits were asked to participate, since we could not predict who would ultimately be eligible for treatment escalation. Participants were recruited from one of three outpatient Rheumatology settings: 1) clinic visit at an academic medical center with an attending rheumatologist or nurse practitioner, 2) clinic visit at an academic medical center with a fellow supervised by an attending rheumatologist, and 3) visit in a private office with an attending rheumatologist. Participants were recruited and consented by the research coordinator or treating provider. All enrolled patients consented to be audiotaped. The impression and recommendation sections of clinic notes were initially reviewed by a single research assistant (PBF) to screen for phrases that indicated increased disease activity or intolerance to current therapy, then subsequently double-checked by a rheumatologist (LF) to determine if the audiotape was suitable for transcription. Audiotapes corresponding to notes documenting increased disease activity or medication intolerance requiring discontinuation were then transcribed. Transcripts eligible for inclusion in this study were those in which increased disease activity was discussed.

Data Collection and Analyses

We use the term disease-modifying anti-rheumatic drug (DMARD) to refer to both conventional and biologic DMARDS, cDMARD to refer to conventional DMARDS, and bDMARD to refer to biologics and tofacitinib. We developed a quantitative coding scheme based on the model proposed by Elwyn et al.(6) to measure specific aspects of SDM. We describe “choice talk” by examining specific options discussed during the visit, which included changes to route of administration, dose of a current DMARD, and/or the addition (or switch to) a new DMARD(s). Specific sets of choices offered are described in Table 2. We assessed “option talk” by evaluating the amount of information clinicians used to describe new choices. For each visit, we report whether clinicians described: details of

administration, the number of potential benefits, the number of potential adverse events (AEs), the mechanism of action, and the cost of the medication(s) (Table 3). We evaluated “decision talk” by examining whether patients vocalized his/her values and/or preferences (Figure 1) and whether there was deliberation between the patient and provider. Deliberation was defined as a discussion between the patient and provider that included the pros and/or cons of available options and took the patient’s values and/or preferences into account. In the post-test phase, we also report whether the value clarification tool was used to facilitate choice, option, and decision talk.

We defined treatment escalation as either increasing the dose of the current cDMARD, changing the route of administration of MTX, or adding/switching a cDMARD or bDMARD. For two cases (one in pre- and one in the post-test phases) in which treatment decisions included the dose escalation of a current cDMARD and the addition of a new cDMARD, we classified this combination as an addition of a new cDMARD when assessing option talk, decision talk and the final treatment decision. As prednisone was frequently discussed as part of the treatment plan, we also evaluated if the three steps of decision-making model were applied to decisions regarding prednisone. We then considered if the final decision(s) for escalation (Table 4) and/or prednisone was concordant with the patients’ values and/or preferences. We considered the chosen medication as the patient’s final decision, even if the treatment plan was dependent on future laboratory results and/or pre-authorization. The study was approved by our institution’s Human Research Protection Program.

RESULTS

Demographic and Clinical Characteristics

In the pre-test phase: 98 patients refused to participate, 496 consented, and 95 audiotapes were transcribed of which 46 met inclusion criteria. In the post-test phase: 59 patients refused to participate, 196 consented, and 61 audiotapes were transcribed of which 40 met inclusion criteria. The majority 84.9% of the participants were women and 69.9% were White. The mean (SD) age was 58.9 (12.7) years. Overall, 36.8% had a four-year college degree or higher; 18.4% were employed full-time, and 44.9 % were married. The mean (SD) disease duration was 12.5 (10.2) years; the majority of patients had moderate disease activity with mean (SD) Clinical Disease Activity Index (CDAI) of 18 (9.6) and mean (SD) Routine Assessment of Patient Index Data (RAPID3) of 12.5 (7.6). Most patients were seen by an attending physician or nurse practitioner alone (73.9% during the pre-test and 80% during the post-test phases); the remainder were seen by both a fellow and an attending level physician. Overall, 10 attendings, one nurse practitioner and seven fellows participated in both phases. Additional information and characteristics are described in Table 1.

Choice Talk

All changes offered are described in Table 2 (combinations that were not discussed, e.g., change in route of administration versus new DMARD(s), are not included). Choice talk included changes to, or addition of, one or more DMARD alternatives in all but one visit in the pre-test phase (in which the treatment discussion was limited to a short course of

prednisone) and in all 40 visits during the post-test phase. In both phases, choices included an increase in dose and/or change in route of administration to the cDMARD only. In the pre-test phase, irrespective of possible changes in dose or route of administration, 34.8% of visits included a discussion describing one new DMARD and 47.8% two or more new DMARDs. In the post-test phase, there was a shift towards a greater number of options being offered, with 27.5% of visits describing one new DMARD and 60% two or more new DMARDs. Of note, all patients, except for one during the pre-test phase, were eligible for at least two new DMARDs.

Patients were offered an average (SD) of 1.5 (0.8) and 1.7 (0.7) choices during the pre-test and post-test visits respectively. cDMARDs were offered more frequently during the pre- than the post-test phase (45.7% versus 20%), while bDMARDs (19.6% versus 30%) and the choice of cDMARD(s) and/or bDMARD(s) (6.5% versus 27.5%) were offered less frequently in the pre- compared to post-test phase. Of the patients eligible for triple therapy (37% in the pre-test and 32.5% in the post-test phases), 10.9% and 12.5% were offered cDMARD(s) to complete triple therapy in the pre- and post-test phases, respectively. Patients who were on tumor necrosis factor inhibitors at the time of their visit were offered an average of 1.4 (0.55) options in the pre-test and 2.1 (1.1) options in the post-test phase.

Option Talk

For the patients offered dose escalation as the sole option (six patients in the pre-test and four in the post-test phase), providers discussed details of administration (83.3% versus 100%), 1–2 potential benefits, and either 0 (83.3% versus 75%), 1–2 (0 versus 25%) or 3–4 (16.7% versus 0) AEs, in the pre- and post-test phases of the study, respectively. For the one patient offered change of route as the sole option in the post-test phase, and the single patient offered the option of dose escalation and change of route in the pre-test phase, the provider discussed details of administration and 1–2 potential benefits. For these choices, mechanism of action or cost was not discussed in either phase.

Details of how new DMARD options were described are included in Table 3. For the patients offered one new DMARD, providers and patients discussed details of administration in the majority of visits and an average (SD) of 1.3 (0.6) potential benefits in the pre-test phase and 1.5 (0.5) potential benefits in the post-test phase (specific frequencies are in Table 3). Providers also described an average (SD) of 1.3 (0.9) and 0.9 (0.8) AEs in the pre- and post-test phases, respectively. Mechanism of action and cost were infrequently discussed in both phases.

For the patients offered two or more DMARDs, providers and patients discussed an average (SD) of 1.5 (0.7) potential benefits in the pre-test phase and 1.6 (0.7) potential benefits in the post-test phase, as well as an average (SD) of 1.5 (1.2) and 1.5 (1.1) AEs in the pre- and post-test phases respectively. While discussion of mechanism of action, potential benefits, and AEs occurred similarly in both phases, details of administration and cost were brought up more frequently in the post-test phase.

Decision Talk

Overall, value clarification occurred in 69.6% of the pre-test and 95% of the post-test visits. Among the small number of visits in which the provider only discussed changes in dose escalation and/or route of administration of a cDMARD, more patients vocalized their values and/or preferences in the post-test (five out of five visits) compared to the pre-test phase (four out of seven visits). In addition, more patients vocalized their values and/or preferences for discussions in which the providers described one new DMARD (90.9% versus 56.3%) and two or more new DMARDs (95.8% versus 86.4%) in the post-test phase than the pre-test phase of the study (Figure 1).

Overall, deliberation occurred in a similar number of pre- and post-test visits during which patients' values and/or preferences were vocalized [81.3% (26 out of 32) of the pre-test and 89.5% (34 out of 38) of the post-test visits]. Deliberation for the small number of decisions related to dose escalation and/or route of administration occurred in three out of four pre-test visits and five out of five post-test visits. Deliberation also occurred in 88.9% of the pre-test and 100% of the post-test visits for decisions related to one new DMARD and in 78.9% of the pre-test and 82.6% of the post-test visits for decisions related to two or more new DMARDs. In visits during which providers recommended one medication over another, providers were more likely to base their recommendations on patients' values and/or preferences during the post-test (100% of six visits) than pre-test (64.3% of 14 visits) visits.

Treatment Decisions Made

Treatment escalation occurred in 32 (69.6%) visits in the pre-test and 28 (70%) visits in the post-test phase. The specific treatment changes are detailed in Table 4. For most visits in which escalation did not occur, providers and patients postponed the decision (n=12 in the pre-test and n=11 in the post-test phases), for following reasons: to optimize time course of current regimen prior to declaring medication failure (33.3% versus 72.7%), to wait for another specialist's input (58.3% versus 0), to enable the patient to review additional information provided about a new DMARD (e.g., home reading material) prior to making decision (8.3% versus 9.1%), or because of the impracticality of changing medications (e.g., patient moving to new location) (0% versus 18.2%), in the pre- and post-test phases of the study, respectively.

Decision concordance with patient values was examined in visits during which both patient values and/or preferences were vocalized and a decision whether to escalate treatment was made at the time of the visit. Decisions were concordant in almost all visits during both the pre- and post-test phases of the study [21 out of the 24 (87.5%) visits in the pre-test and 26 out of the 27 (96.3%) visits in the post-test phase]. In the pre-test phase, there was one visit with a discordant decision in which a patient who initially expressed preference for oral medications was prescribed an injectable bDMARD and two visits where it was unclear whether the patients' values were concordant with the prescribed treatments. In the post-phase, there was one visit where it was unclear whether the patient's values were concordant with the decision.

While prednisone was not included in the value clarification tool, more patients vocalized their values and/or preferences regarding prednisone in the post-test (87.5%) compared to the pre-test phase (66.7%) (Figure 1). Deliberation regarding prednisone occurred in a similar number of visits in both phases [11 out of 20 (55%) pre-test visits and 12 of the 21 (57.1%) post-test visits]. Similarly, providers based their recommendations regarding prednisone on patients' values and/or preferences in 19 out of 20 visits (95%) in the pre-test phase and 21 out of 21 visits (100%) in the post-test phase. Decisions regarding prednisone were concordant with stated patient values and/or preferences in 85% (17 out of 20) of the pre-test and 95.2% (20 out of 21) of the post-test phases. In the pre-test phase, there were two visits with discordant decisions regarding prednisone in which patients who initially expressed unwillingness to take prednisone were persuaded to take prednisone, and one visit where it was unclear whether the patient's values were concordant with the prescribed prednisone. In the post-test phase, there was one visit with a discordant decision regarding prednisone in which a patient was persuaded to take prednisone.

Use of the Value Clarification Tool

The tool was used in the majority (82.5%) of visits during the post-test phase. The tool was used to point out available treatment options (26.5%), as well as differences in route of administration (3%), AEs (2.7%), and benefits (3.2%). It was used to clarify patients' values and/or preferences in 82.5% and to clarify patients' preference for a medication in 12.5% of the visits. The average (SD) length of the visit was 29.9 (11.6) minutes in the pre-test phase and 25.1 (10.7) minutes in the post-test phase.

DISCUSSION

This study evaluated whether a value clarification tool could support SDM for T2T decisions at the point-of-care. We found greater evidence of SDM in the post-test phase of the study as demonstrated by a trend towards patients being offered more choices, a higher number of visits in which certain medication attributes (especially cost) were discussed, and more visits in which patients vocalized their values and/or preferences, compared to the pre-test phase. In addition, providers were more likely to base their recommendations on patients' values and/or preferences in the post-test than pre-test phase. The proportion of treatment decisions concordant with patient values was very high in both phases of the study, suggesting that once values are vocalized, the probability of concordance is high.

Deliberation occurred with equal frequency in both phases during visits in which values were vocalized, indicating that no additional prompting is required once values are discussed. Because the tool increases the likelihood of values and/or preferences being discussed, it would be expected to improve the likelihood of deliberation in clinical practice, albeit, indirectly.

Decision aids have been shown to improve medical knowledge and decrease decisional conflict,(11) but providing patient decision support at the point-of-care to facilitate SDM remains a challenge.(12) We sought to address this gap by using a value clarification tool that enabled patients to potentially match with one or more of five distinct phenotypes describing treatment preferences; thus enabling patients to view how other patients' values

vary, and to match, rather than construct, preferences. The former is a more rapid cognitive task that may be better suited to decision-making at the point-of-care.(13)

Given the increasing number of decision aids available, Elwyn et al.(14) developed the International Patient Decision Aid Standards instrument (IPDASi) to assess the quality of and provide globally accepted standards for decision aids. In accordance with the IPDASi, our tool was developed based on a rigorous stated preference survey, used plain language, provided structured guidance in communication between the patient and provider through the use of explicit preference phenotypes, and helped patients clarify and express values and/or preferences.

Our results are largely consistent with three other decision aids developed for RA patients who were eligible for a change in therapy. Two were designed for use prior to the encounter (15, 16) and one for during the visit.(17) Fraenkel et al.(15) developed and evaluated the use of an interactive web-based decision aid designed for RA patients who were candidates for biologic therapy in a randomized controlled trial. The decision aid resulted in improved knowledge and a higher possibility of making an informed, values-concordant choice compared to usual care at the time of the decision-making. Nota et al.(16) assessed the use of a web-based decision aid for patients with inflammatory arthritis eligible for either initiation or change of a DMARD in a pre-post test study. Patients in the post-test period reported having a more active role in decision-making and were more likely to arrive at decision concordant their values and/or preferences. There were no differences, however, in patients' satisfaction with the decision-making process or adherence.(16) Barton et al (17) evaluated the use of a point-of-care decision aid that was developed for RA patients with low-health literacy who were eligible for a medication change. Results showed that use of the decision aid improved knowledge and reduced decisional conflict.(17) Similar to these studies, we found a shift toward a higher number of choices (two or more) offered to patients with use of the value clarification tool (16) and a comparable number of treatment escalations.(17) Other decision aids exist for different purposes. Martin et al (18) evaluated the effect of different information formats of a decision aid for a hypothetical RA medication and found that experimental design can impact how the effects of a medication are communicated. Li et al (19, 20) evaluated the use of two online decision aids for RA patients to be used at home or in clinic: ANSWER (19) was designed for RA patients unsure about starting methotrexate and ANSWER-2 (20) was intended for RA patients who were recommended to start a biologic or small-molecule agent or switch to a new one. ANSWER (19) was evaluated using a pre-post study with results that showed improvement in patients' decisional conflict and knowledge and ANSWER-2 (20) was evaluated in a mixed-methods, pre-post study with results showing that patients also had decreased decisional conflict as well as improvement in perceived self-management capacity—however, patient-physician communication was not measured in either one.

In order to obtain an objective measure of SDM, we audiotaped all visits. Thus, we were able to describe in detail how the value clarification tool impacted patient-provider communication through review of the discussions, compared to patient-reported outcomes measured in previous studies.(15–20) In addition, the audiotapes allowed us to time the visits.(21) Visits in the post-test phase were, on average, shorter. This may be because the

tool promoted a more efficient discussion focused on what mattered most to each individual patient.

There are also limitations to our study. Ideally, only patients eligible for escalation would be recruited to examine the impact of the decision aid. However, this is difficult to do without additional resources to help identify patients eligible for treatment escalation prior to the visit. Another limitation is the lack of generalizability of our findings to men and ethnic minority groups, as the majority of our participants were female and white. Future studies are needed to evaluate applicability to other groups. In addition, we did not assess whether the decision reached during the visit was actually implemented (i.e., whether the medication was approved by the patient insurance carrier and whether the patient filled the prescription). Furthermore, we had substantial buy-in by several providers at our institution and acknowledge that uptake is dependent on the support from both the physicians, nurses and other clinic support staff. In addition, we are unable to distinguish if greater SDM transpired during the post-test visits due to increased patient education because we did not include an objective measure of knowledge. Lastly, we were unable to provide patients with an accurate estimate of their out-of-pocket cost during the SDM process, despite this issue being a significant factor for the majority of patients.(22) Given the lack of comparative cost data available for the individual patient during a clinical encounter, further investigation is needed to determine how best to discuss cost at point-of-care.(23)

In summary, we found that a value clarification tool illustrating variability in treatment preferences of a large RA patient population could be used to support SDM at point-of-care without prolonging visit time. The results of this study support evaluating the effectiveness of the tool in a large-scale trial.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Appendix

Final version of the value clarification tool.

REFERENCES

1. Gremese E, Salaffi F, Bosello SL, et al. Very early rheumatoid arthritis as a predictor of remission: A multicentre real life prospective study. *Ann Rheum Dis* 2013;72:858–62. [PubMed: 22798566]
2. Grigor C, Capell H, Stirling A, et al. Effect of a treatment strategy of tight control for rheumatoid arthritis (the TICORA study): A single-blind randomised controlled trial. *Lancet*. 2004;364:263–9. [PubMed: 15262104]
3. Singh JA, Saag KG, Bridges SL Jr., et al. 2015 American College of Rheumatology guideline for the treatment of rheumatoid arthritis. *Arthritis Rheumatol*. 2016;68:1–26.
4. Elwyn G, Frosch D, Thomson R, et al. Shared decision making: A model for clinical practice. *J Gen Intern Med* 2012;27:1361–7. [PubMed: 22618581]
5. Charles C, Gafni A, Whelan T. Decision-making in the physician-patient encounter: Revisiting the shared treatment decision-making model. *Soc Sci Med* 1999;49:651–61. [PubMed: 10452420]
6. Greenfield S, Kaplan SH, Ware JE Jr., Yano EM, Frank HJ. Patients' participation in medical care: Effects on blood sugar control and quality of life in diabetes. *J Gen Intern Med* 1988;3:448–57. [PubMed: 3049968]
7. Tapp H, Shade L, Mahabaleshwarkar R, Taylor YJ, Ludden T, Dulin MF. Results from a pragmatic prospective cohort study: Shared decision making improves outcomes for children with asthma. *J Asthma*. 2017;54:392–402. [PubMed: 27813670]
8. Levinson W, Kao A, Kuby A, Thisted RA. Not all patients want to participate in decision making. A national study of public preferences. *J Gen Intern Med* 2005;20:531–5. [PubMed: 15987329]
9. Wang SY, Kelly G, Gross C, et al. Information needs of older women with early-stage breast cancer when making radiation therapy decisions. *Int J Radiat Oncol Biol Phys* 2017;98:733–40. [PubMed: 28366581]
10. Kiesler DJ, Auerbach SM. Optimal matches of patient preferences for information, decision-making and interpersonal behavior: Evidence, models and interventions. *Patient Educ Couns* 2006;61:319–41. [PubMed: 16368220]
11. Stacey D, Legare F, Lewis K, et al. Decision aids for people facing health treatment or screening decisions. *Cochrane Database Syst Rev* 2017;4:CD001431. [PubMed: 28402085]
12. Agoritsas T, Heen AF, Brandt L, et al. Decision aids that really promote shared decision making: The pace quickens. *BMJ*. 2015;350:g7624. [PubMed: 25670178]
13. Fraenkel L, Nowell WB, Michel G, et al. Preference phenotypes to facilitate shared decision-making in rheumatoid arthritis. *Annals of the Rheumatic Diseases Published Online First*: 15 12 2017. doi: 10.1136/annrheumdis-2017-212407..
14. Elwyn G, O'Connor AM, Bennett C, et al. Assessing the quality of decision support technologies using the International Patient Decision Aid Standards instrument (IPDASi). *PLoS One*. 2009;4:e4705. [PubMed: 19259269]
15. Fraenkel L, Matzko CK, Webb DE, et al. Use of decision support for improved knowledge, values clarification, and informed choice in patients with rheumatoid arthritis. *Arthritis Care Res (Hoboken)*. 2015;67:1496–502. [PubMed: 26195173]
16. Nota I, Drossaert CH, Taal E, Vonkeman HE, Haagsma CJ, van de Laar MA. Evaluation of a patient decision aid for initiating disease modifying anti-rheumatic drugs. *Arthritis Res Ther* 2016;18:252. [PubMed: 27793171]
17. Barton JL, Trupin L, Schillinger D, et al. Use of low-literacy decision aid to enhance knowledge and reduce decisional conflict among a diverse population of adults with rheumatoid arthritis: Results of a pilot study. *Arthritis Care Res (Hoboken)*. 2016;68:889–98. [PubMed: 26605752]
18. Martin RW, Brower ME, Gerald A, Gallagher PJ, Tellinghuisen DJ. An experimental evaluation of patient decision aid design to communicate the effects of medications on the rate of progression of structural joint damage in rheumatoid arthritis. *Patient Educ Couns* 2012; 86:329–334. [PubMed: 21752570]
19. Li LC, Adam PM, Backman CL, et al. A Proof-of-Concept Study of ANSWER, A Web-Based Methotrexate Decision Aid for Patients with Rheumatoid Arthritis. *Arth Care Res* 2014; 66:1472–1481.

20. Li LC, Shaw C, Lacaille D, et al. Effects of a Web-Based Patient Decision Aid on Biologic and Small Molecule Agents for Rheumatoid Arthritis, ANSWER-2: A Proof-of-Concept Study. *Arthritis Care Res* 2018; 70(3):243–253.
21. Gravel K, Legare F, Graham ID. Barriers and facilitators to implementing shared decision-making in clinical practice: A systematic review of health professionals' perceptions. *Implement Sci* 2006;1:16. [PubMed: 16899124]
22. Alexander GC, Casalino LP, Meltzer DO. Patient-physician communication about out-of-pocket costs. *JAMA*. 2003;290:953–8. [PubMed: 12928475]
23. Meluch AL OWH. Physician-patient communication regarding patients' healthcare costs in the US: A systematic review of the literature. *J Commun Healthc*. 2015;8.

Significance and Innovations

- We developed a value clarification tool illustrating a set of rheumatoid arthritis treatment preference phenotypes.
- In a pre-post test study, we found that the use of the tool increased the number of visits in which patients vocalized their values and/or preferences about potential treatment options, allowing more providers to base their recommendations on what mattered most to patients during visits in which a recommendation was made.
- This study supports the feasibility of using RA preference phenotypes at the point-of care to support shared decision-making.

Figure 1. Patient vocalization of values and/or preferences

This figure depicts the percent of visits that patient vocalization of values and/or preferences occurred when discussing one new DMARD, two or more new DMARDs, or prednisone. The orange bars depict the percent of pre-test visits and the blue bars depict the percent of post-test visits.

Table 1.

Participant Characteristics

Variable	Pre-Test Phase n=46	Post-Test Phase n=40
Age, mean (SD)	58.3 (13.0)	59.6 (12.4)
Female (%)	40 (87%)	33 (82.5%)
Race (%)	n=46	n=37 *
White	33 (71.7%)	25 (67.6%)
Black	6 (13%)	7 (18.9%)
Other	7 (15.2%)	5 (13.5%)
Hispanic (%)	12 (26.1%)	6 (15%)
Education (%)	n=29	n=28
Some high school	1 (3.5%)	5 (17.9%)
High school graduate	11 (37.9%)	8 (28.6%)
Some college or 2 year degree	4 (13.8%)	7 (25%)
College graduate	4 (13.8%)	3 (10.7%)
Graduate degree	9 (31%)	5 (17.9%)
Marital (%)	n=44	n=34
Single	12 (27.3%)	6 (17.7%)
Married	21 (47.7%)	14 (41.2%)
Widowed	4 (9.1%)	0
Separated/Divorced	6 (13.6%)	13 (38.2%)
Other	1 (2.3%)	1 (2.9%)
Job (%)	n=43	n=33
Full-time	8 (18.6%)	6 (18.2%)
Part-time	4 (9.3%)	2 (6.1%)
Student	1 (2.3%)	1 (3.0%)
Retired	11 (25.6%)	9 (27.3%)
Unemployed	12 (27.9%)	9 (27.3%)
Disability	7 (16.3%)	6 (18.2%)
Insurance (%)	n=44	n=34
Private	15 (34.1%)	10 (29.4%)
Medicare	16 (36.4%)	17 (50%)
Medicaid	13 (29.6%)	5 (14.7%)
Military	0	2 (5.9%)
Erosive disease (%)	17 (46%),n=37 *	17 (56.7%),n=30
Duration, mean (SD)	13.5 (11.6),n=27	11.2 (8.1),n=21
CDAI	15.1 (9.9),n=20	21.3 (8.3),n=17
Rapid3	11.3 (7.8),n=18	13.3 (7.6),n=24
Rheumatoid factor positive (%) **	24 (52.2%)	19 (47.5%)

Variable	Pre-Test Phase n=46	Post-Test Phase n=40
Anti-cyclic citrullinated peptide antibody positive (%) ***	19 (41.3%)	17 (42.5%)
Current prednisone dose		
None	25 (54.3%)	23 (57.5%)
5 mg/day or less	12 (26.1%)	13 (32.5%)
6–10 mg/day	7 (15.2%)	2 (5%)
11–19 mg/day	2 (4.3%)	2 (5%)
20 mg/day or more	0	0
Current DMARD		
Methotrexate	24 (52.2%)	22 (55%)
Hydroxychloroquine	18 (39.1%)	16 (40%)
Sulfasalazine	8 (17.4%)	9 (22.5%)
Leflunomide	6 (13.0%)	2 (5%)
Cyclosporine	0	1 (2.5%)
Azathioprine	0	3 (7.5%)
Etanercept	2 (4.3%)	3 (7.5%)
Adalimumab	3 (6.5%)	2 (5%)
Certolizumab	1 (2.2%)	1 (2.5%)
Golimumab	0	1 (2.5%)
Abatacept	2 (4.3%)	3 (7.5%)
Rituximab	1 (2.2%)	2 (5%)
Tocilizumab	0	1 (2.5%)
Tofacitinib	0	4 (10%)

* Numbers included for variables with missing data.

** Not including visits in which the RF antibody status was either negative (n=13 in pre-test, n=15 in post-test) or unknown (n=9 in pre-test, n=6 in post-test).

*** Not including visits in which the CCP antibody status was either negative (n=15 in pre-test, n=14 in post-test) or unknown (n=12 in pre-test, n=9 in post-test).

Table 2.

Choice Talk

Choice(s) Presented	Pre-Test Phase n=46	Post-Test Phase n=40
<i>Choices not involving a new DMARD</i>	7 (15.2%)	5 (12.5%)
Dose escalation	6 (85.7%)	4 (80%)
Change in route	0	1 (20%)
Dose escalation + change of route	1 (14.3%)	0
<i>Choices involving one new DMARD</i>	16 (34.8%)	11 (27.5%)
One new cDMARD to complete triple therapy	2 (12.5%)	0
One new DMARD	13 (81.3%)	10 (90.9%)
Dose escalation + one new cDMARD	1 (6.3%)	1 (9.1%)
<i>Choices involving two or more new DMARDs</i>	22 (47.8%)	24 (60%)
Two or more new DMARDs	15 (68.2%)	14 (58.3%)
Two new cDMARDs to complete triple therapy	1 (4.5%)	0
New cDMARD(s) to complete triple therapy vs. new bDMARD(s)	1 (4.5%)	2 (8.3%)
Dose escalation vs. two new cDMARDs to complete triple therapy vs. new bDMARD(s)	0	1 (4.2%)
Change of route vs. new cDMARD(s) to complete triple therapy vs. new bDMARD(s)	1 (4.5%)	2 (8.3%)
Dose escalation vs. two or more new DMARDs	3 (13.6%)	4 (16.7%)
Dose escalation + change of route vs. two or more new DMARD(s)	1 (4.5%)	1 (4.2%)

Table 3.

Option Talk

Components Discussed	Pre-Test Phase (n=46)	Post-Test Phase (n=40)
<i>Option = One new DMARD</i>	16 (34.8%)	11 (27.5%)
Details of administration	11 (68.8%)	8 (72.7%)
Number of potential benefits		
0	0	0
1–2	13 (81.3%)	6 (54.5%)
3–4	2 (12.5%)	5 (45.5%)
>4	1 (6.3%)	0
Number of adverse effects		
0	3 (18.8%)	4 (36.4%)
1–2	8 (50%)	4 (36.4%)
3–4	3 (18.8%)	3 (27.3%)
>4	2 (12.5%)	0
Mechanism of action	3 (18.8%)	2 (18.2%)
Cost	2 (12.5%)	2 (18.2%)
<i>Option = Two or more new DMARDs</i>	22 (47.8%)	24 (60%)
Details of administration	13 (59.1%)	21 (87.5%)
Number of potential benefits		
0	1 (4.5%)	0
1–2	11 (50%)	12 (50%)
3–4	9 (40.9%)	10 (41.7%)
>4	1 (4.5%)	2 (8.3%)
Number of adverse effects		
0	6 (27.3%)	6 (25%)
1–2	6 (27.3%)	5 (20.8%)
3–4	3 (13.6%)	9 (37.5%)
>4	7 (31.8%)	4 (16.7%)
Mechanism of action	5 (22.7%)	5 (20.8%)
Cost	4 (18.2%)	12 (50%)

Table 4.

Treatment Decisions Made

Decision	Pre-Test Phase (n=46)	Post-Test Phase (n=40)
Escalation	32 (69.6%)	28 (70%)
Escalated dose and/or changed route of current cDMARD	10 (31.3%)	5 (17.9%)
Escalated to prednisone alone	1 (3.1%)	3 (10.7%)
Escalated to complete triple therapy	3 (9.4%)	1 (3.6%)
Escalated to new cDMARD	10 (31.3%)	10 (35.7%)
Escalated to new bDMARD	8 (25%)	9 (32.1%)
Did not escalate	14 (30.4%)	12 (30%)
Postponed treatment decisions	12 (85.7%)	11 (91.7%)
Refused	2 (14.3%)	1 (8.3%)