New RA Treatment Strategy: Online Tools for Health Literacy

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About half of rheumatoid arthritis patients don't understand enough information to make intelligent treatment choices. Here's how to help.

Source: Rheumatology Network

Early, aggressive treatment vastly improves rheumatoid arthritis (RA) outcomes, but only when it is actually used. Less than half of newly diagnosed patients are taking disease-modifying drugs (DMARDs), and many say they don't know enough to make informed choices on the subject. Also, there are some treatment disparities.

Nearly one-third of RA patients surveyed for a recent report in the *Journal of Rheumatology* felt they had not been well enough informed to allow shared decision-making (SDM). Low health literacy, lack of trust in their physician, and limited English proficiency were all associated independently with poor SDM.

This puts a new onus on rheumatologists to make sure that RA patients fully understand their disease and their treatment options. To this end, researchers in the US and Europe are developing new patient education materials, including online learning modules about RA, decision-making aids, self-monitoring tools, YouTube videos -- and even ways for patients to have a voice in treatment guidelines. Reports on these initiatives have appeared in recent weeks, both in journals and at the European League Against Rheumatism (EULAR) 2014 annual meeting in Paris.

Two new decision-making tools

The Patient Decision Aid (PtDA) from the Netherlands and the ANSWER online tool from Canada can help resolve doubts and conflicts patients may feel about medications like methotrexate (MTX). RA patients assigned to use the PtDA tool took a more active role in decision-making than controls, the Dutch researchers said at EULAR, and felt their final choice of medication to be more consistent with their personal values.

The Canadian decision tool, a series of videos called ANSWER (for ANimated, Self-serve WEb-based Research tool) helped 60% of test subjects resolve conflicts and make a decision about taking MTX. But results like this can be undermined by poor health literacy--defined as an inability to "obtain, process, and understand" basic health information sufficiently to make appropriate decisions. We've already reported accumulating evidence of a disconnect between how doctors think their RA patients feel and what the patients actually say about their symptoms, which interferes with care. But there may also be a big disconnect between what doctors tell their patients and what they actually understand.

Over their heads?

Nearly one-half of US adults are hobbled by limited health literacy, particularly the elderly and ethnic minorities. This includes as many as 10% of RA patients.

What will they misunderstand? Directions for taking medications. Self-care instructions. How to fill out questionnaires. Information about RA that they find online. Much of this information simply goes over their heads.

A recent analysis of 23 patient resources on RA, systemic lupus erythematosus, vasculitis, and osteoarthritis (OA) found all of them written above an 8th-grade reading level, rather than at the 6th grade level as generally recommended for health information. Only five of these 23 resources received superior “suitability” scores.

An April 2014 study involving more than 6,000 RA patient volunteers bore this out. It used two single-item questions to determine health literacy. When asked how often they needed "to have someone help you when you read instructions, pamphlets, or other written material from your doctor or pharmacy," 7% of subjects responded “sometimes,” “often,” or “always.” More than 4% responded "not at all" or "a little bit" to the question “How confident are you filling out medical forms by yourself?”
The study, published in *Arthritis Care & Research*, found that RA patients with low health literacy had poorer self-reported medication adherence and higher scores on the Health Assessment Questionnaire (HAQ) disability index than others. Other research suggests that low health literacy defeats treat-to-target strategies, increasing medication errors, leading to flares and relapses, and boosting medical costs. But even college-educated patients may walk out of the rheumatologist’s office with a poor recall of what they heard during the visit. Studies show most patients visiting a doctor retain only about half of what was discussed.

**What you can do**

In addition to new patient education initiatives, tools are being developed to help rheumatologists counter limited health literacy. The Thurston Arthritis Research Center at the University of North Carolina in Chapel Hill, collaborated with experts in the health literacy to create a “**Toolkit for Rheumatology**.”

The toolkit is based on the concept of “universal precautions,” actions that minimize risk when it’s unclear which patients may be affected. It offers almost two dozen tools and suggestions to improve education, communication, and services in key areas of clinical practice:

- **Spoken communications**: Before you start talking, pause to consider the patient’s culture, socioeconomic status, and facility with language. Limit content to three or five main topics, and encourage questions. Use the “teach-back” method to confirm that you got through: Ask patients to repeat what you’ve just told them.

- **Written communications**: Printed or online materials should use “plain” language – simpler, but not dumbed-down language – that most people can understand easily. This should apply to medication dosage instructions, consent forms, discharge orders, and basic information about RA, nutrition and prevention. Identify and use easy-to-read patient forms and questionnaires.

- **Patient self-management and empowerment**: Encourage questions (again, tackling one question at a time), create “action plans” with your patients, and ask for feedback on how you can work together to improve medication adherence.

- **Support systems**: Encourage staff to link your patients to medication resources: Financial assistance plans from pharmaceutical companies and state governments, non-medical community supports, and health literacy services in your area.

**References:**


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