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# Do visual aids influenced patients' risk perceptions for rare and very rare risks?

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### ABSTRACT

**Objective:** To examine whether visual aids (a graphic representation and/or conceptual illustrations) influence patients' risk perceptions for rare and very rare risks.

**Methods:** Participants were randomized to a scenario which varied by probability of infection (2% or 0.2%) and visual aid: numbers only, numbers + graphic representation, numbers + conceptual illustrations, or numbers + graphic representation + conceptual illustrations. Risk perceptions and likelihood of starting the medication were examined across the four formats, separately, in participants with and without a college education.

**Results:** Adding a graphic representation and/or conceptual illustrations did not affect risk perceptions among those with a higher level of education. Adding both a graphic representation + conceptual illustrations decreased risk perceptions and increased likelihood of starting the medication among participants randomized to the 2%, but not 0.2% scenario, among participants with lower levels of education.

**Conclusion:** Adding a graphic representation + conceptual illustrations to numbers may influence perceptions for rare, but not very rare, risks among patients with lower education.

**Practice Implications:** Clinicians should be aware of the differential effects of visual aids developed to facilitate risk communication. Patients with higher levels of education may be less responsive to visual aids than those with lower education.

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## 1. Introduction

Patients with rheumatic diseases are being increasingly asked to participate in treatment decisions with their physicians. This is especially true for clinical scenarios in which multiple options exist, such as escalating care to treat-to-target in rheumatoid arthritis. In order to effectively participate in medical decisions, patients must be able to differentiate between competing risks. While informed decision making does not require patients to be able to recall specific verbatim numeric information, it does require patients to be able to distinguish between a rare and very rare (e.g., 1% versus a 0.1%) probability of a serious adverse event.

However, a large body of evidence has shown that people do not attend to numeric information when making decisions [1–3]. This is especially true for those that involve affect-rich outcomes, such as rare, but serious, treatment-related complications [4]. Because of the fear or dread associated with these outcomes, people tend to overweigh risks of rare events in their decisions [5]. Overweighing these risks is particularly problematic in clinical scenarios where failure to attend to numeric information results in objectively poorer outcomes. For example, one of the major barriers to implementing treat-to-target strategies in rheumatoid arthritis is patients' reluctance to start new medications associated with very rare, albeit serious, adverse events [6].

Studies across many disciplines have sought to improve risk communication and comprehension using visual aids. Icon arrays and bar graphs are among those most frequently used, and have been shown to improve the accuracy of expectations related to treatment outcomes [7,8]. Whether these visual aids help patients

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differentiate between rare and very rare levels of risk, however, is not known.

Patients' beliefs about their health and medications have a strong influence on their decision making and behavior [9]. A large literature based on Leventhal's illness perception theory has demonstrated the importance of causal attribution and patients' explanatory models of their disease and treatment on their decisions and adherence [10,11]. Moreover, some interventions focused on changing illness perceptions have had a positive impact on patient outcomes [12,13]

A commonly cited barrier to treatment among patients with rheumatic diseases is the fear of taking medications which suppress the immune system [14]. In order to examine whether addressing this fear could influence patient decision making, we designed a series of three balance scales illustrating the effect of disease and treatment on the immune system: one illustrated imbalance due to an overactive immune system, the second illustrated a balance achieved through appropriate medication, and the third illustrated an opposite imbalance due to an underactive system. The series of s did not include quantitative information. Their objective was to modify patients' qualitative gist understanding of immune-system treatments, thereby reducing fear of treatment and enabling them to better attend to probabilistic information.

In this study, we sought to examine the impact of different visual aids on patients' ability to differentiate between a rare and very rare adverse event. We randomized patients to view numeric data alone, with a graphic representation, with conceptual images of a series of three consecutive balance scale illustrations depicting how medications regulate the immune system, or with the combination of both the graphic representation and conceptual illustrations. We hypothesized that addition of visual aids would influence patients' risk perceptions for rare and very rare risks compared to numeric information only. Because of the influence of education on risk perceptions, willingness to take medication as well as the impact of graphic representations [8,15,16], we examined the influence of visual aids on patients with lower (not college graduates) and higher levels of education (college graduates) separately.

## 2. Methods

### 2.1. Participants

All English-speaking patients receiving care at an academic rheumatology practice, who had at least three visits in any 12 consecutive months between May 2014 and November 2016, were mailed a survey and a preaddressed stamped envelope. At the end of the survey, participants were given the opportunity to mail back their contact information to be entered into a raffle to win one of eight Amazon \$50 gift cards.

### 2.2. Scenario

Participants were asked to imagine that their symptoms had worsened and that their physician was recommending a new medication using the following scenario:

Imagine that for the past 3 weeks your disease is getting worse even though you are taking your medications. You feel more tired and have a lot more pain. You are having trouble doing the activities you were able to do a month ago. You are also having trouble keeping up with your responsibilities. Your blood tests show that your disease is worse. You see your rheumatologist who tells you about a different medication that may help you. The medication is taken as a pill once a day. It is covered by your insurance and it does not interact with your other medications.

This new medication helps about 65% (65 per 100) of people. The only serious side effect is the risk of an infection that needs to be treated in the hospital for about 5 days with intravenous antibiotics. These infections most commonly happen in the lungs (called pneumonia), skin or kidneys.

The medication was described using eight scenarios (manipulated using a  $2 \times 4$  design). We varied the probability of infection (2% or 0.2%) and the risk presentation format. Risk was described using one of four formats: numbers only, numbers + graphic representation, numbers + conceptual illustrations (a series of three consecutive balance scale illustrations), or numbers + graphic representation, + conceptual illustrations. Numbers were presented as probabilities well as natural frequencies in all formats. An example of the graphic representation and conceptual illustrations are illustrated in the Appendix. Route of administration, benefit, and cost were held constant. Each subject responded to a single, randomly-assigned scenario.

### 2.3. Measures

Likelihood of starting the medication was measured on a 5-point scale anchored by Not likely at all and Very likely. We measured risk perceptions by asking participants how risky they thought the medication was and how worried they were about the risk of infection, both measured on 5-point scales. Risk-benefit expectation was measured by asking participants to choose one from the following five statements (scored from 1 to 5): 1= The benefits of taking the new medication greatly outweigh the risks; The benefits of taking the new medication slightly outweigh the risks; The benefits of taking the new medication are equal to the risks; The risks of taking the new medication slightly outweigh the benefits; 5= The risks of taking the new medication greatly outweigh the benefits. Lastly, we collected demographic (age, gender, ethnicity) and clinical characteristics (disease duration, current treatment, global impact of disease). Global impact was measured by asking participants to rate the following item: "Considering all the ways in which your disease may affect you, please indicate how you have been doing over the past week" on an 11-point numeric rating scale (0= Very well, 10= Very poorly).

### 2.4. Analyses

We first compared participant characteristics across the four visual aid groups using ANOVA or chi-squared tests as appropriate. We then examined the associations between the two levels of probability (2% versus 0.2%), visual aids, and education with the four dependent variables (DVs): perceived riskiness (higher scores indicate higher perceived riskiness), perceived worry (higher scores indicate higher perceived worry), risk-benefit expectation (higher scores indicate worse risk-benefit expectations), and likelihood of starting the medication (higher scores indicate higher likelihood to start) in separate ANOVAs. Because of the strong association of education with each DV demonstrated in the preceding ANOVAs, we compared ratings of the four DVs in participants with versus without a college education. That is, within each education group, we compared participants' ratings for the two levels of probability (2% versus 0.2%) using t-tests for each of the four DVs separately. We did not correct for multiple comparisons. We had 85% (or greater) power to detect an effect size of 0.3 (or greater) for each of these comparisons assuming an alpha of 0.05 (one-tailed). We subsequently used mixed linear models to adjust for patient characteristics which can impact preference and risk perceptions (age, perceived global impact of disease, and current treatment with a disease-modifying or immunosuppressive drug). Lastly, we examined ratings for subjects randomized to the numbers, numbers + graphic

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