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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.

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 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 2×4 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.

2.2 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).

2.3 Analyses

2.3.1 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 representation, numbers + conceptual illustrations, or numbers + graphic representation + conceptual illustrations compared to ratings for subjects randomized to the numbers-only condition for the 2% and 0.2% scenarios. This paper reports additional planned analyses using data collected from a previously published study. (17) The study was determined to be exempt by our institution’s Human Research Protection Program.

3. Results

A total of 2093 surveys were mailed and 655 participants returned completed surveys. The mean age (SD) was 59.2 (14.4) years (range 21–90). Most were woman (78.7%), Caucasian (84.0%), and 48.6% were college graduates. The mean (SD) patient global impact score was 4.1 (2.8), the median disease duration was 13.1 years (range 0.5 to 62 years), and 68.4% were currently on a disease-modifying or immunosuppressive medication. Participants’ characteristics did not differ across the four risk presentation formats.

In four separate omnibus models, education was associated with each DV, ($p < 0.05$). Participants who were not college graduates ($n = 337$) rated the medication as being riskier

[Mean (SD)= 3.0 (1.22) vs. 2.90 (0.89), $p= 0.01$], were more worried about the risk of infection [Mean (SD)= 3.20 (1.16) vs. 2.94 (1.07), $p= 0.002$], had worse risk-benefit expectations [Mean (SD)= 2.27 (1.22) vs. 1.97 (2.00), $p= 0.001$], and were less likely to start the medication [Mean (SD)= 2.27 (1.22) vs. 1.97 (2.00)], 3.56 (1.22) vs. 3.75 (1.14), $p= 0.04$] compared to those who were college graduates ($n= 318$).

Mean ratings for perceived riskiness, worry, risk-benefit expectation, and likelihood of starting the medication for scenarios associated with a 2% versus 0.2 % risk of infection for participants with and without a college education are provided in Table 1. Among college graduates, there was no difference between responses to the 2% and the 0.2% scenarios. In contrast, for participants who were not college graduates, presentation format did result in some differences between evaluations of a 2% versus 0.2% risk. Participants randomized to the graphic representation condition describing a 2% risk of infection rated riskiness higher than participants randomized to the same visual aid describing a 0.2% risk of infection. However, no differences in worry, risk-benefit expectation, or likelihood of taking the medication were observed between these two groups.

The only other visual aid associated with differences between the two risk levels among participants without a college education was the combined numbers + graphic representation and conceptual illustrations format. Participants' ratings for perceived riskiness, worry, and risk-benefit expectation were lower, and likelihood of taking the medication was greater, for the 2% compared to the 0.2% scenario. Differences remained significant in multivariate models including age, patient perceived global impact of their disease, and current treatment with a disease-modifying or immunosuppressive drug (Table 2).

Among participants randomized to the 2% scenario who did not have a college education, ratings for worry (Figure 2) and risk-benefits expectations (Figure 3) were lower, and likelihood of starting the medication (Figure 4) higher, in the combined numbers + graphic representation and conceptual illustrations format compared to the numbers-only format. Differences in perceived riskiness were not statistically significant (Figure 1). In contrast, ratings for the combined and numbers-only format for the 2% risk did not differ relative to the numbers-only format for the 0.2% risk scenario (Figures 1 through 4), for both subjects with and without a college education.

4. Discussion and Conclusion

4.1 Discussion

In this study, adding a visual aid to numbers did not affect risk perceptions or preferences, among subjects with a higher level of education. Hence, rare and very rare medication risks were treated as “about the same” by college graduates across all conditions.

Others have also demonstrated less effect of visual aids among subjects with higher levels of education and/or numeracy.(8, 16, 18) In this study, college graduates may have had pre-existing perceptions of these drugs (e.g., due to higher prior knowledge) and therefore may have been less impacted by additional information. Alternatively, they may have been more confident in their own knowledge and/or beliefs, and may have overlooked the additional

information describing risks. Regardless of the underlying mechanism, these results add to the literature supporting the need for new strategies to help highly educated patients incorporate different levels of risk into their decisions.

In contrast, significant differences between rare and very rare risks were observed among patients with less education when both a graphic representation and conceptual illustrations were added to the numbers-only condition. Participants with some or no college education, unexpectedly perceived less riskiness, were less worried, had more favorable risk-benefit expectations, and were more likely to take the medication associated with a greater risk (2%) than a lower risk (0.2%) of infection. This seemingly paradoxical effect was due to the combined condition having an impact on risk perceptions and preferences for the 2%, but not the 0.2% scenario. The combined format appeared to close the gap between lower and higher educated participants in the 2% condition--reducing perceptions of risk, worry, and risk-benefit expectations, and increasing likelihood of starting among those with lower education.

It is important, however, to note that these comparisons were generated by a between-subjects design. Varying level of risk within subjects, although limited by order effects, would permit direct comparisons.

It is not clear why the combined visual aid was effective for the 2% risk but had little effect on the 0.2% risk, especially since both conditions also included the corresponding natural frequency format (i.e. 2 per 100 people and 2 per 1,000 people respectively). One hypothesis is that appreciating place value as conveyed by a decimal point was challenging for the less-educated.(19) It is also possible that the added information overly increased complexity for the abstract probability concept. Moreover, graphic representations describing larger populations (and illustrating a larger number of icons) tend to increase perceptions related to the severity of the described outcome compared to equivalent numeric risk descriptions.(20)

Compared to the numbers-only format, the combined format resulted in more favorable ratings among less educated subjects viewing the 2% scenario; however, no consistent differences were found for either the graphic representation or conceptual illustrations alone. This finding suggests that the conceptual illustrations may have had an impact on participants' mental representations of risk associated with the graphic representation, but not the numbers only format. Numerous studies have compared graphic representations to other risk presentation formats (18, 20–26); however, the effect of combining formats is not well understood. Future studies using cognitive interviews, think aloud protocols, or hypothesis-driven experiments are needed to better understand the differential impact of the graphic representation and/or conceptual illustrations for rare and very rare events.

To the best of our knowledge this is the first study using a randomized experimental design to examine the influence of explanatory images addressing the underlying mechanism of treatment specifically targeted to patients' illness perceptions on a treatment decision associated with two levels of risk compared to the well-studied graphic representations in a large patient population. Unlike other decision-support tools which typically describe risks and benefits separately, the conceptual illustrations provide patients with an integrated view

of both the risks and benefits of treatment. Important limitations of our study include the use of a hypothetical scenario, which does not replicate decisions taking place in clinical practice. In addition, our participation rate was 31.3%, which limits the generalizability of our results. We did not control for multiple comparisons, and it is possible that positive results were due to Type I errors.

4.2 Conclusion

In summary, our findings suggest that adding explanatory images consistent with patients' illness perception to a graphic representation and numerical descriptive information may influence perceptions and preferences for rare, but not very rare, risks among patients with lower education. Future research is needed to understand the mechanisms underlying this effect, and why visual aids did not impact participants' evaluations of very rare (0.2%) risks.

4.3 Practice Implications

Clinicians should be aware of the differential effects of visual aids used to facilitate risk communication. Specifically, 1) visual aids may not affect how patients evaluate very rare risks, and 2) patients with higher levels of education may not be affected by visual aids when evaluating medications.

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Fig. 1.
Perceived riskiness for a 2% and 0.2% risk of AE across all four formats.

Fig. 2.
Perceived worry for a 2% and 0.2% risk of AE across all four formats.

Fig. 3.
Risk-benefit expectation for a 2% and 0.2% risk of AE across all four formats.

Fig. 4.
Likelihood of starting the medication associated with a 2% and 0.2% risk of AE across all four formats.

Table 1.

Risk perception and preference ratings across presentation formats

	Serious Infection (%)	Perceived Riskiness ¹ Mean (SD)	Worry ² Mean (SD)	Risk-Benefit Expectation ³ Mean (SD)	Likelihood of Starting ⁴ Mean (SD)
College Graduate					
Numbers Only					
n = 40	2%	2.88 (0.91)	2.78 (1.14)	1.95 (1.02)	3.63 (1.08)
n = 38	0.20%	2.95 (0.84)	2.84 (0.97)	2.08 (1.19)	3.66 (1.17)
	p-value	0.72	0.78	0.61	0.90
Numbers + Graphic Representation					
n = 34	2%	3.12 (1.09)	3.00 (1.21)	2.00 (1.37)	3.79 (1.27)
n = 47	0.20%	2.81 (0.92)	2.83 (1.05)	1.87 (1.06)	3.83 (1.17)
	p-value	0.19	0.51	0.65	0.90
Numbers + Conceptual Illustrations					
n = 41	2%	3.02 (0.82)	3.10 (0.94)	2.10 (1.22)	3.61 (1.22)
n = 32	0.20%	2.81 (0.69)	3.13 (0.87)	2.00 (1.05)	3.58 (0.94)
	p-value	0.25	0.90	0.72	0.92
Numbers + Graphic Representation + Conceptual Illustrations					
n = 46	2%	2.87 (0.88)	3.04 (1.13)	1.78 (0.99)	3.96 (1.07)
n = 40	0.20%	2.77 (0.95)	2.83 (1.17)	2.05 (1.31)	3.90 (1.22)
	p-value	0.63	0.39	0.28	0.82
Not College Graduates					
Numbers Only					
n = 44	2%	3.00 (0.78)	3.25 (1.06)	2.43 (1.21)	3.33 (1.22)
n = 41	0.20%	3.05 (0.92)	3.29 (1.27)	2.44 (1.16)	3.45 (1.18)
	p-value	0.79	0.87	0.98	0.69
Numbers + Graphic Representation					
n = 39	2%	3.41 (0.91)	3.38 (1.07)	2.10 (1.10)	3.38 (1.43)
n = 39	0.20%	2.87 (0.86)	2.97 (1.33)	2.15 (1.29)	3.69 (1.26)
	p-value	0.01	0.14	0.85	0.32
Numbers + Conceptual Illustrations					
n = 40	2%	3.18 (0.87)	3.43 (1.15)	2.38 (1.21)	3.55 (1.10)
n = 42	0.20%	3.12 (0.80)	3.24 (1.10)	2.43 (1.36)	3.49 (1.19)
	p-value	0.76	0.46	0.86	0.82
Numbers + Graphic Representation + Conceptual Illustrations					
n = 45	2%	2.82 (0.91)	2.64 (1.17)	1.84 (1.09)	4.13 (0.94)
n = 47	0.20%	3.26 (0.94)	3.40 (0.99)	2.42 (1.30)	3.45 (1.32)
	p-value	0.028	0.001	0.022	0.005

¹. Perceived riskiness: Higher scores equate to greater perceived riskiness.

- ².Worry: Higher scores equate to greater perceived riskiness.
- ³.Risk-Benefit expectations: Higher scores equate to risks judged as outweighing the benefits.
- ⁴.Likelihood of starting: Higher scores equate to higher likelihood of starting the medication.

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Table 2.

Multivariable models examining the association of probability of risk with risk perceptions and likelihood of starting the medication for participants without a college education randomized to the numbers + graphic representation + conceptual illustration condition.

	DF	F value	P value
Perceived riskiness			
Risk (2% vs 0.2%)	85	7.77	0.0065
Age	85	0.73	0.3960
Global impact	85	3.37	0.0698
Current treatment	85	0.16	0.6864
Worry			
Risk (2% vs 0.2%)	85	12.88	0.0006
Age	85	0.69	0.4100
Global impact	85	1.58	0.2125
Current treatment	85	1.43	0.2351
Risk-benefit expectation			
Risk (2% vs 0.2%)	85	5.70	0.0192
Age	85	1.09	0.3004
Global impact	85	2.58	0.1120
Current treatment	85	0.46	0.4992
Likelihood of starting			
Risk (2% vs 0.2%)	85	9.43	0.0029
Age	85	1.34	0.2509
Global impact	85	0.38	0.5406
Current treatment	85	0.08	0.7798