

Measuring Patient Preferences

An Overview of Methods with a Focus on Discrete Choice Experiments

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KEYWORDS

- Patient preference • Discrete choice experiment • Rheumatoid arthritis
- Rheumatic disease • Review • Method • Bias

KEY POINTS

- Patient preference measures differ from patient-reported outcomes. The latter measures a patient's health status, while the former measures the value patients place on a health outcome.
- Patient preferences can be quantified either in absolute (eg, 0–1, where 0 is death and 1 is full health) or relative terms.
- A discrete choice experiment quantifies the relative importance of treatment attributes by asking patients to choose between treatments that differ in their attributes.
- A discrete choice experiment is a powerful tool for understanding patient preferences that is growing in popularity. Like any measurement tool, it requires careful consideration and understanding of potential biases, which we review in this article.

INTRODUCTION

To understand how patient preferences can be measured, we must first define what patient preferences are. Broadly speaking, a preference is an expression of desirability of one alternative over another. In a health care context, this can be clarified as the relative importance of alternative management options or outcomes related to health.¹ These alternative options will often be different treatments or treatment strategies, but

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can also be diagnostic alternatives or other choices that patients face. Anytime a choice exists, a preference can be stated.

Patient preferences should be distinguished from patient-reported outcome measures (PROMs) and patient-reported experience measures that are widespread in rheumatic disease research and clinical care.¹ The use of PROMs and patient-reported experience measures in rheumatic diseases have been recently reviewed in an issue of *Rheumatic Disease Clinics of North America*.² PROMs measure a patient's health state in 1 or more domains at a given point in time. In contrast, patient preferences seek to understand the importance of this health (or any other) outcome relative to something else. For example, the Health Assessment Questionnaire Disability Index is a PROM that measures a patient's functional status. A measure of patient preferences would ask whether a patient would prefer a given functional state (or improvement in function) over, for example, an improvement in pain. Alternatively, the value of both function and pain could be elicited on an absolute scale (eg, 0–1, where 0 is death and 1 is full health) and then compared.

WHY SHOULD WE MEASURE PATIENT PREFERENCES?

Shared decision making is a model whereby patients and clinicians work together to reach a decision aligned with patients' values, and is widely regarded as the preferred medical decision-making approach.³ The shared decision-making model recognizes that, although physicians are experts in disease diagnosis and management, patients have unique preferences that should be elicited and considered in treatment decisions. Measuring the preferences for a population of patients is not necessary for the individual encounter, because each patient will have their own preferences that should be considered. Measuring patient preferences, however, can identify which decisions are most preference sensitive and, therefore, most critical for shared decision making. Studies routinely demonstrate that physicians are poor judges of patients' preferences.⁴ Understand patient preferences through objective measurement can help to clarify these misconceptions.

Patient preferences also often vary, and understanding the factors that are associated with risk aversion or risk seeking can inform decision making. Preferences for rheumatoid arthritis treatment have been associated with both disease characteristics (including disease severity,⁵ disease duration,⁵ and prior treatment experience^{6,7}) and sociodemographics (including age,⁸ employment status,⁹ education level,¹⁰ income,⁸ and ethnicity^{9,10}). This knowledge may help to inform the development or implementation of strategies to promote shared decision making. The association between preferences and sociodemographics also highlights the importance of tailoring decisions to the patient as a whole, rather than just their disease severity.

Understanding patient preferences can also help to inform policy decisions and treatment recommendations. Patient preferences are a critical step in the Grading of Recommendations, Assessment, Development and Evaluation (GRADE) process,¹¹ which has been adopted by the American College of Rheumatology (ACR). Under the GRADE approach, strong recommendations are reserved for situations in which most patients, on the balance of benefits and harms, would choose a particular treatment approach. Fraenkel and colleagues¹² provided an example of how incorporating patient preferences may impact treatment recommendations for rheumatoid arthritis. In a pilot study, they presented the same evidence on treatment risks and benefits used by the physician dominated ACR guideline panel to a patient panel trained in the GRADE approach. For 3 of 16 treatment recommendations, the patient panel recommended a different treatment, and the strength of the recommendation (confidence

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