Review

Measuring patient-centered care: An updated systematic review of how studies define and report concordance between patients' preferences and medical treatments

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ABSTRACT

Objective: The purpose was to examine recent advances in measuring value concordance and to highlight best practices.
Methods: The paper updates a prior systematic review. A systematic review of the literature from 2008 to 2012 identified articles that reported a relationship between patients' preferences concerning health outcomes and/or medical treatments, and treatment (intended or actual). Relevant articles were independently abstracted by two reviewers.
Results: The search identified 3635 unique citations, the full text of 187 articles was examined, and 63 articles covering 61 studies were included, nearly a third more articles than identified in the original review. There were 72 different value concordance calculations, the majority of which were clearly reported with significance. More studies assessed knowledge, reported on the association between value concordance and knowledge, and included a decision aid compared to those in the original review.
Conclusion: There is increased reporting of value concordance in the literature. However, large differences exist in the way that the measure is defined and calculated. The variability makes it difficult to draw conclusions about the quality of care across studies.
Practice implications: Value concordance is a critical component of patient-centered care, and further attention is needed to establish standards for measurement and reporting.

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1. Introduction

Patient-centered care is defined as "healthcare that establishes a partnership among practitioners, patients, and their families (when appropriate) to ensure that decisions reflect patients' wants, needs and preferences and that patients have the education and support they need to make decisions and participate in their own care" [1]. In 2001 the Institute of Medicine (IOM) identified patient-centered care as one of its six aims in its landmark *Crossing the Quality Chasm* report [1]. There have been global initiatives to assist patients and their providers in the decision-making process; among them the establishment of a Health Evidence Network (HEN) by the World Health Organization (WHO)/Europe [2], and the formation of the International Patient Decision Aid Standards Collaboration (IPDAS) [3]. However, while support has grown for the concept of patient-centered care, the ability to provide patient-centered care and to measure the extent to which it occurs has been traditionally hampered by gaps in the health care system [4,5].

One method of assessing patient-centered care is through measuring decision quality, which has been defined as the extent to which treatments reflect the considered preferences of well-informed patients and are implemented [6,7]. A key part of decision quality is that patients are well informed about the evidence on the clinically appropriate options and outcomes [8]. Another core element of decision quality is concerned with value concordance, or how well the treatment aligns with the patient's goals and preferences [9].

In 2008, two of the authors [EO and KS] conducted a systematic review to assess approaches used to calculate value concordance [6]. Specifically, value concordance was defined as the association between patients' preferences concerning health outcomes and/or medical treatments, and treatment intention or treatment undergone [6]. Forty-nine relevant articles were identified, and these revealed a diverse picture in terms of how investigators conceptualized and measured the concordance between patients' preferences and their treatment [6]. The variation in what and how to measure and report concordance limited the ability to generalize results and led to some recommendations regarding how "preferences" should be defined, how "choices" (treatment) should be defined, and appropriate methods for calculating the association between these concepts [6].

Since 2008, a number of initiatives have been undertaken to promote patient-centered care and there has been a growing emphasis on the ability to measure decision quality. In the U.S., the Patient Protection and Affordable Care Act recently established a new Center for Medicare and Medicaid Innovation (CMMI) and provided a significant funding stream for the Patient Centered Outcomes Research Institute (PCORI). Both of these initiatives include shared decision-making (SDM) among their key areas of focus [10]. In the U.K., SDM and the use of patient decision aids have been emphasized in government health policy [11,12] and in legislation [13]. SDM is a collaborative process between patients and their providers whereby health care decisions are made together using both the best available scientific evidence and incorporation of patient preferences [14].

With a greater shift toward patient-centered care and the emergence of delivery system redesign initiatives, it is reasonable to reevaluate whether such efforts have led to care that reflects patients' desires, and whether investigators have adopted consistent approaches to measure the extent to which this is happening. An update of the prior systematic review was therefore undertaken to evaluate the state of measurement of concordance, or the association between patients' preferences and treatments.

2. Methods

The methods closely match what was done in the prior systematic review [6] and follow the guidelines promoted by Preferred Reporting Items for Systematic reviews and Meta-Analyses (PRIMSA) [15]. MEDLINE and PsychINFO databases were searched with key terms such as: preferences, preference measures, attitude measures, or utility theory; and prediction, estimation, or predictability measurement; and decision making, decision theory, choice behavior, decision trees, decision support systems, or decision support techniques. A secondary strategy targeted additional resources, including the current Cochrane Review of Decision Aids and references found within identified articles. The full search algorithm used to identify potential studies in the electronic databases is included in Appendix A. The search was limited to journal articles, in English, published in peer-reviewed journals, dealing with humans, with publication dates from 2008 through 2012.

To be included in the review, studies were required to examine medical decisions and report on (1) patients' preferences concerning health outcomes and/or medical treatments, (2) treatment intention or treatment undergone, and (3) a relationship between preferences (for specific health outcomes and/or treatments) and treatment (intended or actual). We limited the definition of preferences, used as the independent variables in the calculations, to patients' preferences for health outcomes or attributes of treatments or their preferred treatments (as opposed to preferences for participation in decisions, which can be considered another type of concordance). The preferences for health outcomes could be elicited via attitude surveys or utility-based methods. Treatment intention could either be assessed by directly asking patients or determined via a calculation (e.g. model or summary score). Treatment intention was used as the independent variable (the "preference") in some studies and as the dependent variable in other studies (for example, in studies where data collection was limited to a single patient survey and did not follow up to assess treatment received).

Finally, value concordance or the relationship between the independent ("preferences") and dependent ("treatment") variables needed to be calculated and reported. Studies that only reported on patients' perceptions of concordance, such as "I am clear about which benefits matter most" or "My decision shows what is most important to me" were not considered to be measuring concordance for the purpose of this review.

The authors reviewed the titles and abstracts of the candidate publications identified using the described search algorithm (see Appendix A). From this initial list, articles were excluded from further review if they (1) did not deal with a medical situation (e.g. studies of nutrition and school kids, studies presenting a new methodology for modeling, studies focusing on mate selection, studies of hypothetical medical decisions not relevant to study participants), (2) dealt with a medical situation, but were not focused on decision making for tests and treatments (e.g. predictive models of mortality or adverse events, predictive performance of guidelines, cancer staging models, psychometrics for survey instruments), (3) generally dealt with medical decision making, but did not present data on patient preferences or choices (e.g. clinical decision support tool for diabetes management, review papers or papers presenting clinical guidelines for management, diagnosis, or treatment of specific condition, study using standardized patients to examine clinical decision making), (4) were systematic reviews or literature reviews (although articles included in such reviews were assessed to identify potential articles relevant to this systematic review), or (5) were qualitative studies with data on preferences and choices not categorized in a quantitative manner. Qualitative studies that only reported generalizations or themes, e.g. "patients were not always