

REVIEW

A measurement framework for adherence in patient decision aid trials applied in a systematic review subanalysis

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Abstract

Objective: To explore how studies of decision aids conceptualize and measure adherence and to evaluate the effect of patient decision aids on adherence.

Study Design and Setting: A subanalysis of adherence studies included in the 2014 Cochrane review on patient decision aids. An adherence framework for decision aid trials is presented which includes two types of adherence: “adherence to choice” and “adherence to treatment.” Included studies were classified based on the adherence framework, and their impact on adherence was assessed.

Results: Thirteen trials involving 2,115 patients were included. Of these 13, eight measured “adherence to choice” and 10 measured “adherence to treatment.” There was considerable heterogeneity in how adherence was measured, with studies varying in whether they considered baseline choice, follow-up choice, or neither, and whether they presented separate or aggregated adherence measures. No studies measuring “adherence to choice” reported significant differences between the decision aid and comparator, whereas four studies measuring adherence to treatment reported a statistically significant difference between the decision aid and comparator, with three favoring the decision aid arm.

Conclusions: The adherence framework provided insight into important measurement factors. There remains considerable heterogeneity in measures of adherence which makes it difficult to draw conclusions. © 2016 Elsevier Inc. All rights reserved.

Keywords: Adherence; Compliance; Persistence; Patient decision aids; Shared decision making

1. Introduction

Adherence is defined by the World Health Organization as “the extent to which a person’s behavior—taking medication, following a diet, and/or executing lifestyle changes, corresponds with agreed recommendations from a health

care provider” [1]. Despite widespread acceptance of the importance of adherence, and decades of research aimed at improving it [2], adherence rates to many treatments remain virtually unchanged at around 50% in the developed world [1,3,4].

There is growing understanding that the social context of patients’ lives may have a great impact on their ability to adhere to a treatment and integrate changes into their daily lives [5]. Numerous barriers to adherence have been identified, including poor patient-provider communication, and patients’ attitudes and beliefs toward health and illness [6]. The consequences of poor treatment adherence are significant. At the individual level, poor adherence can result in increased morbidity or premature mortality [2], whereas

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What is new?

Key findings

- Patient decision aids have the potential to increase adherence by increasing patient knowledge, participation in decision making, and improving patient-provider communication.
- We introduce an adherence framework that is relevant to patient decision aid trials and distinguishes between two types of adherence: “adherence to choice” and “adherence to treatment.”

What this adds to what was known?

- Through a subanalysis of trials included in the Cochrane review on patient decision aids, we apply the adherence framework and find there is considerable heterogeneity in how adherence has been conceptualized, measured, and reported.

What is the implication and what should change now?

- Based on this analysis, we provide recommendations for future decision aids trials, which can help standardize the measurement and reporting of adherence.

at the health system level, it can increase costs, with estimates suggesting it is responsible for over \$100 billion in annual health care costs in the United States alone [7]. Few interventions targeting adherence demonstrate a positive effect, and those that do are often complex, costly, and offer only marginal benefit [3,7–9].

When attempting to improve adherence, it is useful to differentiate between unintentional and intentional nonadherence [10]. An example of unintentional nonadherence is when a patient forgets to take their medication. Behavioral interventions to improve unintentional nonadherence might include handouts with dosing instructions, simplified dosing, or reminders through programmed devices, text messages, or special packaging [3]. By comparison, intentional nonadherence is when a patient makes an explicit choice not to initiate or continue to follow the recommended treatment. Concerns about the side effects of treatment, costs, time commitment, and impact on daily activities may be more important to the patient than the potential treatment benefits [6]. Intentional nonadherence may be perfectly rational if taking a treatment causes the patient additional social, personal, or clinical harms [11]. If a patient believes that a treatment is not in their best interest, interventions such as reminders or simplified dosing are unlikely to improve adherence.

One potential approach for reducing intentional nonadherence is through shared decision making (SDM) [12]. SDM treatment decisions are based on a therapeutic alliance between the patient and provider, in which both parties openly exchange their respective experiential and clinical knowledge to reach a mutually agreed on course of action, which may include agreeing to disagree [5]. Evidence suggests that patients who receive a treatment they prefer may be more motivated to adhere and willing to tolerate side effects, which in turn may result in improved health outcomes [13–17]. Patient decision aids are the most well studied SDM interventions [18]. They have been developed for a range of treatment decisions and have been shown to increase patient knowledge, result in more realistic expectations of potential harms and benefits, increase patient participation in decision making, and result in patients choosing options that match with their values [18]. A number of these outcomes, including greater knowledge, higher participation in decision making, and better patient-health provider communication, have been identified as important factors for adherence [12,19,20].

A Cochrane Systematic Review reporting on 115 randomized controlled trials of patient decision aids finds that “although several studies have measured adherence, the variability in the measurement makes it difficult to determine the effects of patient decision aids on adherence” [18]. This sentiment is echoed by a previous narrative review that describes large heterogeneity in studies [12]. In light of this evidence, which suggests that the term adherence is being used in a variety of different ways in decision aid trials, we begin by introducing an adherence framework that has relevance to the decision aid literature. We then perform a subanalysis of randomized controlled trials from the Cochrane review of decision aids, which allows us to classify articles according to the framework. Doing so will allow us to answer the following questions: (1) How has adherence been conceptualized, measured, and reported? and (2) What is the effect of decision aids on adherence?

2. Conceptualization of adherence for decision aid trials: a proposed framework

To assess the trials included in this analysis, we propose a framework to categorize measures of adherence that will provide greater clarity on what type of adherence is being measured and how it is being measured. Fig. 1 is a simple decision tree representation of a decision aid compared to usual care where there are two competing treatment options and adherence is assessed at follow-up. At the first node, participants are randomized to either the decision aid arm or usual care. At baseline, a choice is made between treatment options (Treatment X and Treatment Y). Baseline choice is defined as the choice made following administration of the decision aid and consultation with a health professional. At follow-up, the framework considers the follow-up choice

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