Developing a patient-centered medical home: synopsis and comment on “Patient preferences for shared decisions: a systematic review”

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ABSTRACT

The seventh column on Evidence-Based Behavioral Medicine synthesizes a systematic review by Chewning and colleagues (Pat Educ Couns 86:9–18, 2012) on patient preferences for shared decision-making regarding treatment and screening. A total of 115 studies were included in the final analyses. In 63 % of studies, a majority of patients preferred sharing decisions with their primary care physician, as opposed to delegating health decisions to their provider. A time trend appeared such that in studies published more recently, a greater percentage of patients, particularly cancer patients, preferred sharing decisions. Further research should seek to better understand how the decision making of specific patient populations is influenced by life course changes and secular trends. Longitudinal studies can help to elucidate how patient decision-making preferences evolve over the course of illness and health status changes in different medical conditions.

KEYWORDS

Patient-centered medical home, Patient decision role, Patient preferences, Shared decision making

INTRODUCTION

As part of the effort to improve health care in the USA, the organization and delivery of primary care is being transformed. One major transformation that is now taking place involves the development of the Patient-Centered Medical Home (PCMH). The National Committee for Quality Assurance defines PCMH as “a health care setting that facilitates partnerships between individual patients, and their personal physicians, and when appropriate, the patient’s family [4].” According to the Agency for Healthcare Research and Quality (2011), the PCMH comprises five attributes: (1) a patient-centered orientation, (2) comprehensive, team-based care, (3) coordinated care, (4) access to care, and (5) a systems-based approach to quality and safety [1]. Inherent in a patient-centered orientation that emphasizes patients’ singular needs, cultures, and values is an appreciation for patients’ unique preferences for shared clinical decisions. The purpose of this systematic review is to compare

patients’ decision role preferences across various contexts and patient populations.

KEY QUESTION

What are patient decision role preferences, and how do these preferences vary across time, measurement approach, and patient diversity?

SEARCH STRATEGY

The literature search focused on empirical, peer-reviewed journal articles written in the English language between January 1980 and December 2007. The databases used were Ovid MEDLINE, the Cochrane Database of Systematic Reviews, PsychInfo, Web of Science, and PubMed (2005–2007). Keywords searched were “physician–patient relations” and “preferences,” in addition to variations on these main terms. References from the studies generated by this initial search were reviewed to identify other eligible studies. Finally, co-authors searched their collections of relevant literature to locate any manuscripts not identified by the first two steps of the literature search. The first author and an additional coder reviewed abstracts for inclusion. Papers included in the review had to report data categorizing patients by whether they preferred to defer medical decisions to the physician (e.g., “the delegate”) versus wanting to make decisions on their own OR in collaboration with the physician (e.g., participant in decision making). Instruments for measuring patient decision role preferences were varied across studies and included the Autonomy Preference Index, the Control Preferences Card Sort (CPS), the Health Opinion Survey, and the Problem Solving Decision Making Scale (PSDM). Scores on the scales varied from 5–100. Unless another specific algorithm was noted, the midpoint of the score was used to categorize patients as either a “delegate” (e.g., lower scores) or “participant” (e.g., higher scores) in his/her medical decision making. Eligible studies were categorized according to whether participants were: (1) patients with cancer, (2) patients with other chronic diseases, (3) patients undergoing invasive procedures, and (4) general population.

RESULTS

Of 119 studies, 63 % reported that a majority of participants preferred to participate in medical decisions, and 21 % reported that a majority of participants preferred to delegate decisions. Results were then analyzed as a function of three variables: (1) study population, (2) date of publication, and (3) role preference measure. The breakdown of results by study population revealed that more than 75 % of studies of cancer or invasive procedure populations and 50 % of research on those with chronic conditions or general populations found that a majority of the sample preferred participating in decisions. Analyses of the results by date of publication revealed that study participants' expressed preference to participate in medical decisions increased over time. A majority of participants preferred participating in decisions in 43, 51, and 71 % of studies reflecting the following time periods: 1974–1989, 1990–1999, and 2000–2007, respectively. The time trend showing increased preference for shared decision making was strongest among study populations with cancer or other chronic conditions. Finally, results were compared as a function of the measures used to assess patient preference. The proportion of patients expressing a preference for shared decision making varied across measures. Measures such as the CPS or PSDM that explicitly present a response option that endorses shared decision making elicited a higher proportion of patients that endorsed a shared or autonomous decision role.

CONCLUSIONS

The study population plays a significant role in the distribution of those who prefer to participate versus delegate medical decision making. Specifically, cancer and invasive surgery patients are more likely than members of the general population to prefer a “participant” role in decision making. Further, a time trend is evident, such that more recent studies find a larger percentage of patient participants that preferred to participate in medical decision making. Finally, the measures used to assess decision preferences can bias patient responses.

COMMENT

An appreciation for patients' unique preferences regarding the level of participation they wish to have in health decisions is integral to the patient-centered medical home. These findings highlight the degree to which a substantial proportion of patients wish to participate actively in decisions about their health care, as well as the degree to which a preference for shared (in contrast to delegated) decision making has grown more normative over time. Nevertheless, variation in decision-making preferences persists depending upon the patient's medical condition.

An important limitation of current literature on decisional preferences is the lack of complete psychometric data needed to evaluate the reliability and validity of the measures used. This insufficiency of evidence takes on added significance in view of findings that different assessment tools have yielded varied results. Researchers are encouraged to provide full psychometric data, including information about scale scores, derivation of standardized scores, and interpretation rubrics. Additional work also is needed to clarify contemporary understanding of the decision-making construct itself. Improved comprehension is needed about patient perceptions, attitudes, and understandings about the decision-making process, particularly given findings that many are unclear about their opportunities to engage in decision making.

The observation that patients' preferred role changes over time within various health conditions suggests that longitudinal descriptive studies could elucidate the evolution of decisional preferences.

A practical question remains about how to solicit patients' role preferences and tailor visits according to their specific needs. A major rationale for shared decision making is the potential to better engage patients in their own self-care. The need for patient activation around personal health care is especially great because the vast majority of health decisions are made by patients in their daily lives, far from any provider's office. These include choices about whether to exercise, choose healthy foods, practice safe sex, get sufficient sleep, or take prescribed medications. The old paternalistic model of medical decision making needs revision to catch up with the current realities of personal choice and cultural diversity [5, 6]. Brown and colleagues [2] suggest a useful shared decision-making protocol that follows four steps: (1) establish a shared understanding of the patient's illness, (2) present treatment options, (3) discuss the patient's values and lifestyle factors that bear upon the choice of treatment, and (4) present recommended treatment options and solicit patient choice. The current conceptualization of patient decision making needs to be extended beyond initial treatment choice to also encompass decisions about maintenance or change in treatments. That will enable patient preferences and preferred decision roles to be understood across the full trajectory of care.

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