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Patients Want to be Involved

Introduction

Imprecisely worded and poorly designed survey questions have caused considerable confusion about the degree to which patients want to be involved in medical decisions. Perhaps the most frequently cited source of confusion is a 1989 paper by Ende et al. in which the authors concluded: "Patients prefer that decisions be made principally by their physicians, not themselves." This may be an accurate assessment of the answers they collected, but the wording of the questions that generated those answers may have shaped the results.

For example, respondents were asked to rate the degree to which they agreed or disagreed with a series of statements such as: "Hospitalized patients should not be making decisions about their own medical care." In another series, the respondents were instructed to select one of five responses: "the doctor alone," "mostly the doctor," "both equally," "mostly me," and "me along" to a series of questions including: "Who should decide if a chest x-ray should be taken for a sore throat?"

In a 1996 paper, Deber et al. posited that it was reasonable for patients to think physicians should make decisions that they (the patients) perceive to be heavily dependent on detailed clinical knowledge, but that patients should be involved in choosing among options that have been deemed medically reasonable by a physician. She argued that the questions asked by Ende and his colleagues were ambiguous and easily could be interpreted by respondents as referring mainly to technical, clinical decisions.

Deber and colleagues developed questions that clearly differentiated between these two roles: *problem solving*, which requires clinical expertise and *decision making*, which requires input about the patient's goals and concerns. Using the responses developed by Ende ("the doctor alone," "mostly the doctor," etc.) they asked:

- Who should determine what the treatment options are for a patient?
- Who should determine what the risks and benefits are of each treatment option?
- Given all the information about the risks and benefits of the possible treatments, who should decide which treatment option should be selected?

The researchers theorized that the first two questions are related to problem solving, whereas the last question reflects decision making. Using this methodology-- with clear delineation of the medical decision under study-- the investigators found that clear majorities of patients wanted physicians to perform tasks related to problem solving, but want to share or control decision making.

Recent studies on patient involvement

Recent articles have reported on work purporting to measure patients' interest in participating in their medical decisions. The results of these studies have been consistently dependent on the wording of the questions posed. When the decisions could reasonably be seen as technical, or when the types of decisions are unspecified and hence could be assumed to be technical, respondents indicate a preference for doctors to make the decisions. However, when the questions clearly indicate that there is more than one reasonable option and that associated trade-offs relate to information within the patients' areas of expertise (i.e. their lifestyle and personal preferences), clear majorities of patients say they want to be involved in decision making.

In one study, patients were asked whether they agreed or disagreed with the statement: "I prefer to leave decisions about my medical care up to my doctor." About 62 percent of respondents agreed, and the authors concluded, "The majority of patients prefer to delegate decision making (Arora and McHorney, 2000). However, the wording of the question is ambiguous; it does not specify whether the decisions are related to problem solving or decision making.

These results also illustrate another feature of question wording that affects results: the use of the agree/disagree question format. Research has shown that respondents are more likely to agree with a positively worded statement than to disagree with a negatively worded statement (i.e. Schuman and Presser, 1981; Krosnick and Judd, 2007; Dillman and Tarnai, 1991). Moreover, this tendency is exacerbated when the statement in question is ambiguous, such that respondents are not entirely certain what they are being asked.

A survey conducted by Levinson and colleagues (2005) illustrates this point. The researchers asked three questions related to the desire for shared decision making. To be scored as providing a "pro shared decision making answer, respondents needed to agree with a positively worded statement, "I prefer that my doctor offers me choices and asks my opinion," and disagree with two negatively worded statements, such as "I prefer to leave decisions about my medical care up to my doctor." More than 90 percent of respondents agreed "strongly" or "moderately" with the positively worded statement, yet only 34 percent and 41 percent respectively, disagreed "strongly" or "moderately" with statements that were very similar in meaning, but were worded in a negative direction.

These data show that the format-- rather than the content-- of the questions regarding decision making can shape the data results. The authors concluded that the data showed disinterest with sharing in decision making. However, had they worded two of the three questions positively, we believe that the conclusion would have been opposite.

In contrast, Thompson et al. (1993) asked respondents explicitly about how they wanted to participate in making choices between two options that were both deemed medically reasonable; clear majorities wanted to share or take a lead role in the decision. Mazur and Hickham (1997) performed a similar study in a Veterans Administration hospital, making obvious the distinction between the technical elements and the value-based aspects of the decision. Nearly 80 percent of the veteran respondents wanted to share or take lead in decision making.

It is true that some portion of the population will say that they prefer to delegate decisions to their doctors-- no matter the phrasing of the question. However, research, such as the meta-analysis of studies on the effects of decision aids, has shown that providing patients with information about the decision consistently increased their decision to share in decision making (O'Connor et al., 2009).

The experience of patients at Dartmouth-Hitchcock Medical Center supports these research findings. Before making important medical decisions, patients at the medical center routinely receive decision aids and fill out post-viewing questionnaires. Analysis of questionnaire responses relating to fourteen different decisions regarding topics ranging from prostate cancer screening with the PSA test to back surgery, substantiated patients' interest in shared decision making. When asked who should make the decision ("mainly me," "mainly the doctor," or "both equally"), a majority said "mainly me" for all but two of the decisions, and more than 90 percent said either "mainly me" or "both equally" for every one of the 14 decisions.

Coupled with the viewing of a decision aid that supports the idea of shared decision making, the fact that physicians at Dartmouth prescribe aids no doubt helps encourage patients to take a more active role in the decision process.

These additional supports clearly promote the process of shared decision making at the medical center. However, the most salient point about the experience at Dartmouth is the affirmation that when conditions are supportive, patients almost unanimously express a desire to play a major role in medical decision making.

A recent cross-sectional survey of adults, which was conducted by Public Opinion Strategies, provides additional evidence that patients want to be involved in decision making. Respondents were asked to read a statement about informed decision making (shown below) and rate their favorability toward the concept on a scale from 0 to 100.

Informed medical decision making is an idea in health care that patients should receive information about all of the treatment choices and options available to them for a specific disease, illness, or procedure before they decide, in conjunction with their doctor, on the appropriate treatment choices.

With 100 being the most favorable response, the mean rating was 82. Almost 70 percent of respondents rated the statement with a score greater than 80. These data show that when given clearly worded questions about medical decision making, the majority of people want to be involved in an active decision making process with their health care providers.

Conclusion

We believe that the data clearly and consistently show that most people want to be informed and involved in decisions about their medical care. When questions are worded such that patients understand that they are not being asked to make decisions requiring technical clinical information, when questions are worded in formats other than agree-disagree, and particularly when respondents have been given basic information about the decision they are facing, survey data are extremely consistent; most patients want to be informed and to play a direct and active role in the decision making process.

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