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# A typology of preferences for participation in healthcare decision making

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## Abstract

Classifying patients as "active" or "passive" with regard to healthcare decision making is misleading, since patients have different desires for different components of the decision-making process. Distinguishing patients' desired roles is an essential step towards promoting care that respects and responds to individual patients' preferences. We included items on the 2004 Wisconsin Longitudinal Study mail survey measuring preferences for four components of the decision-making process: physician knowledge of patient medical history, physician disclosure of treatment choices, discussion of treatment choices, and selection of treatment choice. We characterized preference types for 5199 older adults using cluster analysis. Ninety-six percent of respondents are represented by four preference types, all of which prefer maximal information exchange with physicians. Fifty-seven percent of respondents wanted to retain personal control over important medical decisions ("autonomists"). Among the autonomists, 81% preferred to discuss treatment choices with their physician. Thirty-nine percent of respondents wanted their physician to make important medical decisions ("delegators"). Among the delegators, 41% preferred to discuss treatment choices. Female gender, higher educational attainment, better self-rated health, fewer prescription medications, and having a shorter duration at a usual place of care predicted a significantly higher probability of the most active involvement in discussing and selecting treatment choices. The overwhelming majority of older adults want to be given treatment options and have their physician know everything about their medical history; however, there are substantial differences in how they want to be involved in discussing and selecting treatments.

*Keywords:* US; Decision making; Patient preferences; Communication; Survey research; Cluster analysis

## Introduction

Successful physician–patient communication about decision making plays a critical role in healthcare delivery, yet there are conflicting messages about changing roles for physicians and patients. A mandatory role for patients as autonomous decision makers has recently been recommended, since patients alone weather the consequences of their medical care (McNutt, 2004). However, others advocate that patients be allowed to participate to the extent they desire, completely delegating decisions to their physicians if they so choose (Whitney, McGuire, & McCullough,

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2004). The model of patient participation where both physician and patient communicate information and values and make decisions together—called shared decision making—has been embraced in literature (Charles, Gafni, & Whelan, 1999; Emanuel & Emanuel, 1992; Quill & Brody, 1996), and the Institute of Medicine has recommended including it in medical school curricula as a mechanism to improve care (Institute of Medicine, 2004). Yet there has been little discussion resolving the potential conflict between promoting shared decision making as ideal and accommodating individual patient preferences for participation (or lack of participation) in decision making.

There is evidence that not all components of the shared decision making model are equally desired by patients. Early work in this area identified two distinct components of patient participation: information exchange and decision making (Ende, Kazis, Ash, & Moskowitz, 1989; Ong, de Haes, Hoos, & Lammes, 1995; Strull, Lo, & Charles, 1984). Later work further refined the components to three: information exchange, deliberation, and decisional control (Charles et al., 1999). It is well established that patients want to receive information from their physicians almost universally (Deber, Kraetschmer, & Irvine, 1996; Ende et al., 1989; Nease & Brooks, 1995), but less is known about information transmission, i.e., patient preferences for providing information to their physicians. Preferences for deliberation (i.e., formal discussion about options) and preferences for decisional control (i.e., power over the final selection of treatment) are known to differ substantially among patients (Robinson & Thomson, 2001), although it is unclear whether patients who prefer discussing treatment options also prefer making the final decision about treatment. Where one study suggests that patients do not want to be involved in problem-solving tasks while retaining control over decisions (Deber et al., 1996), others advise patient involvement in both stages (Quill & Brody, 1996). Often the concept of deliberation as distinct from decisional control is ignored entirely.

Consequently, there is little information available to assist clinicians in understanding and distinguishing the different roles patients prefer in the decision-making process. Distinguishing these roles is an essential step towards promoting patient-centered care, care that respects and responds to individual patients' preferences (Gerteis et al., 1993). Physicians have been classified according to their attitudes about paternalism, patient autonomy, and deliberation (Falkum & Forde, 2001), but patients have not been similarly characterized according to their preferences for participation in multiple, distinct stages of healthcare decision making.

To address this gap, we categorize a population-based cohort of older adults into types based on preferences for participation in each of four components of healthcare decision making (physician knowledge of patient, physician disclosure of treatment choices, discussion of treatment choices, and selection of treatment choice). We then describe the preference types with respect to key socio-demographic and health variables. We use data from the Wisconsin Longitudinal Study (WLS), which for 47 years has followed over 10,000 men and women who graduated from Wisconsin high schools in 1957. Respondents have completed extensive telephone and mail surveys with high sample retention and represent a wide variety of health states.

## *Conceptual model*

Several models of decision making have been described. In the paternalistic model, physicians perform information management, assess options, and make treatment decisions for patients (presumably in patients' best interests) without consideration of patient preferences (Katz, 1984). This model assumes that there are objective criteria to determine the best course of action, that physicians choose this course of action and that patients assent to this course with gratitude (Emanuel & Emanuel, 1992). It is also assumed that patients who prefer not to make the final decision also do not want to participate more than minimally in information exchange or discussing options. Conversely, in the informed or consumer model, physicians provide all relevant information to their patients, and patients alone assess their options and make the final decision. The physician in this model serves as a technical expert to provide information and facilitate decisions made by a fully autonomous patient (Emanuel & Emanuel, 1992). Again assumptions are made about the congruence of preferences for information, deliberation, and decisional control, namely, that patients who want to make the final decision do not want to first discuss all the options with physicians. The shared model merges these models into one where patients and physicians