

Do Low-Numeracy People Avoid Shared Decision Making?

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Objectives: Doctors have been increasingly encouraged to involve patients in decision making rather than pursuing the paternalistic model in which they make the decisions for their patients. But do patients want to participate in making decisions about their health? Is there a relationship between their preferences for shared decision making and numeracy skills? Are those preferences different in countries with different medical systems, and for different age groups? Extant studies cannot answer these questions because most are based on nonprobabilistic, highly selective patient samples that prevent generalizations to a broader population. **Design:** In a survey on probabilistic national samples in the United States and Germany, we interviewed participants with low numeracy skills (Germany: $n = 127$, mean numeracy = 37; United States: $n = 117$, mean numeracy = 36) and high numeracy skills (Germany: $n = 133$, mean numeracy = 96; U.S.: $n = 121$, mean numeracy = 91). **Main Outcome Measures:** Usual and preferred role in medical decision making. **Results:** A significant number of people with low numeracy in both the United States (35%, $SE = 8.2$) and Germany (30%, $SE = 6.1$) preferred to be more passive than they currently were. High-numeracy people, in contrast, were mostly satisfied with their current role. On average, Americans were more active than Germans. Middle-aged participants preferred to be more active compared to both younger and older ones. **Conclusions:** Shared decision-making preferences are related to numeracy skills, country, and age. Education efforts to increase numeracy, as well as using nonquantitative communication formats, may foster involvement of low-numeracy patients in decisions about their health.

Keywords: shared decision making, numeracy, cross-cultural research, paternalistic decision making, risk communication

Doctors have been increasingly encouraged to involve patients in decision making rather than pursuing the paternalistic model in which they make the decisions for their patients (Barry, 1999; Frosch & Kaplan, 1999; Hanson, 2008). However, a number of important issues related to patients' preferences for shared decision making remain unexplored.

First, it is not clear how much patients actually want to participate in medical decision making. Although a number of studies have been conducted on different patient groups, the results are mixed: While some have found strong preferences for shared decision making (Beaver & Booth, 2007; Caress, Luker, Woodcock, & Beaver, 2002; Deber, 1994; Ende, Kazis, Ash, & Moskowitz, 1989; Gaston & Mitchell, 2005; Strull, Lo, & Charles, 1984), other studies are less supportive, in particular those involv-

ing cancer patients (Degner & Sloan, 1992; Frosch & Kaplan, 1999). One reason for these mixed results might be that the role patients usually assume in interactions with medical doctors differs from the role they would prefer to assume. Patients' usual role may be determined by a number of factors independent of their personal preferences, such as the nature of their disease, their doctor's attitude toward shared decision making, the availability and complexity of the information about different treatments, and whether the patients have health insurance. These factors can make patients either more or less active in deciding about their own health than they would like to be. Therefore, in this study we asked not only about the role patients *usually* play in their interactions with doctors, but also about the role they think they *should* play. The latter might be more revealing: The way it diverges from their usual role indicates whether they would prefer to be more active or more passive in their interactions with doctors than they currently are.

We hypothesized that many patients would prefer to play a different role than they usually play. This has important implications for programs aimed at promoting shared decision making. If patients are usually passive and believe that this is the role they should play, then such programs should focus on changing patients' attitudes toward shared decision making. If patients are passive but would like to be more active, then efforts should be made to change doctors' attitudes toward shared decision making. Finally, if patients are active but would prefer to be more passive, then steps should be taken to empower the patients—for instance, through education—to participate in deciding about their health.

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The second unexplored issue is the role of numeracy in preferences for shared decision making. Patients might prefer a passive role in their interactions with doctors because they lack the skills needed to understand the risks and benefits of different medical options. One such important skill is numeracy, which is essential for the understanding and use of quantitative information about health (Ancker & Kaufman, 2007; Galesic, Garcia-Retamero, & Gigerenzer, 2009; Garcia-Retamero & Galesic, 2009, 2010b; Nelson, Reyna, Fagerlin, Lipkus, & Peters, 2008; Peters & Levin, 2008; Peters et al., 2006). People with low numeracy skills, for instance, have less accurate perceptions of the risks and benefits of screening (Davids, Schapira, McAuliffe, & Nattinger, 2004; Donnelle, Arocha, & Hoffman-Goetz, 2008; Schwartz, Woloshin, Black, & Welch, 1997; Woloshin, Schwartz, Black, & Welch, 1999) and are more susceptible to biases in judgments and decisions than those with high numeracy (Fagerlin, Ubel, Smith, & Zikmund-Fisher, 2007; Garcia-Retamero & Galesic, 2009, 2010a; Garcia-Retamero, Galesic, & Gigerenzer, in press; Peters et al., 2006; Reyna & Brainerd, 2007, 2008). This, in turn, can reduce their medication compliance and impair understanding of health risks (Reyna, Nelson, Han, & Dieckmann, 2009). Patients with low numerical ability have more difficulty following a complicated dosing regimen (Estrada, Martin-Hryniewicz, Peek, Collins, & Byrd, 2004) and tend to have a higher history of hospitalization (Apter et al., 2006). Therefore, even when patients receive accurate information about all available options, they may not be able to understand the probabilities of outcomes associated with those options. It may be more difficult for them both to align the options with their personal preferences and to make decisions about their health (Deber, 1994). There is a dearth of published research on how much patients' numeracy skills affect their preferences for shared decision making. In this study, we focused particularly on comparing the decision-making preferences of people with low and high numeracy skills. We hypothesized that even though the usual roles of low- and high-numeracy people might be similar, low-numeracy people might prefer a more passive role in interactions with their doctors.

The third issue is that, so far, most studies on shared decision making have been conducted on convenience samples of specific patient groups (Beaver & Booth, 2007; Caress et al., 2002; Deber, 1994; Degner & Sloan, 1992; Ende et al., 1989; Gaston & Mitchell, 2005; Strull et al., 1984). Although these studies provide valuable information about the preferences of these particular patients, the results cannot be generalized to a wider population due to nonprobabilistic sampling methods. This is problematic because it prevents researchers from reaching conclusions about the effects of important demographic characteristics—such as age (Cassileth, Zupkis, Sutton-Smith, & March, 1980; Degner & Russell, 1988; Ende et al., 1989; Frosch & Kaplan, 1999)—on preferences for shared decision making. For instance, several existing studies have suggested that there is a negative correlation between age and a preference for shared decision making (Cassileth et al., 1980; Degner & Russell, 1988; Ende et al., 1989). However, most of these studies included only patients. As young people in the general population typically have less experience in interacting with doctors, they might in fact be more passive than older groups. We hypothesized that the correlation between age and shared decision-making preferences in the general population is smaller than in the patient samples. To investigate this, we studied shared

decision-making preferences using probabilistic national samples that are representative of general populations.

The final unexplored issue is how shared decision-making preferences differ in countries with different medical practices. Two prominent examples are Germany and the United States. Most health expenditures in the United States are privately based (55%; World Health Organization, 2008), and—at least before the new health reform—a significant part of the population either did not have health insurance (26%) or had sporadic or insufficient coverage (an additional 9%; Schoen, Doty, Collins, & Holmgren, 2005). In contrast, in Germany only 23% of health expenditures are privately based, and most people have health insurance (99.7%; Statistisches Bundesamt Deutschland, 2008). This means that Americans might be required more often than Germans to determine whether they need a medical treatment and which one would be best, given the amount of money they can afford to spend. In addition, patient-targeted advertising of pharmaceutical products is allowed in the United States but not in Germany, adding to the pressure on U.S. patients to make their own decisions about their health. Because of these differences, we hypothesized that the U.S. patients would usually play a more active role in their interactions with doctors than German patients would. We investigated whether these differences are indeed reflected in preferences for shared decision making in the two countries.

Method

Sample

The study was conducted on probabilistic national samples of German and U.S. populations aged 25 to 69 years. The participants were chosen from large panels of households that had been selected through probabilistic telephone surveys of the general population and that had been equipped with Internet access if they did not already have it. These panels, maintained in Germany by the company Forsa (20,000 households, or 11% of those initially contacted) and in the United States by Knowledge Networks (43,000 households, or 16% of those initially contacted), allow researchers to conduct computerized studies over the Internet and enable generalizations to be made from the data to the general population. Participants do not have to own a computer or have Internet access to be included in the panel—they are given the necessary equipment and instructed in its use once they agree to become members of the panel. Such panels have been used successfully in a number of studies in the areas of health and medicine, political and social sciences, and economics and public policy (Baker, Wagner, Singer, & Bundorf, 2003; Jacoby & Sniderman, 2006; Lerner, Gonzalez, Small, & Fischhoff, 2003; Miller, Scott, & Okamoto, 2006; Schlenger et al., 2002). Methodological studies have shown that data from such panels are comparable to the results obtained through traditional probabilistic sampling methods (Chang & Krosnick, 2009).

The present study was included in a larger project funded by the Foundation for Informed Medical Decision Making entitled "Helping people with low numeracy to understand medical information." The project involved a survey that gathered data for a number of studies related to understanding and communicating risks; the survey was conducted in two waves. In the first wave, large national samples of participants ($n = 1,009$ in the U.S. and $n =$

1,001 in Germany) completed a numeracy scale consisting of nine items selected from Schwartz et al. (1997) and Lipkus, Samsa, and Rimer (2001). Participants with numeracy scores in the top and bottom third of the whole sample were invited to the second wave 3 weeks later. A random half of these participants were asked to answer the questions about shared decision making presented in this paper, resulting in the sample structure given in Table 1. This sample enabled us to compare people with low and high numeracy scores within each country, as well as each of those groups between countries.

Response rates were good for this survey mode (see Vehovar, Batagelj, Lozar Manfreda, & Zaletel, 2002). Of the panel members who were invited in the first wave, 52% in Germany and 54% in the United States completed the questionnaire. The respondents were not significantly different from the general population in terms of sex, gender, or age, which suggests low nonresponse bias (detailed comparison of the first-wave sample structure and the general population is presented in Galesic & Garcia-Retamero, 2010). Of those who were invited in the second wave, 83% in Germany and 66% in the United States completed the questionnaire. The response rates among high- and low-numeracy participants were similar in both countries (i.e., it was not the case that low-numeracy participants had lower response rates). Due to lower response rates in the second wave in the United States, we had to invite some participants from the extremes of the middle third of the numeracy list. Therefore, the low- and high-numeracy groups in the United States represent approximately the bottom and top 40% of the population, respectively (instead of 33% as in Germany). Nevertheless, note that the average numeracy scores in both groups were still somewhat lower in the United States (see Table 1), reflecting the overall lower numeracy scores compared to Germany (Galesic & Garcia-Retamero, 2010).

Questionnaire

To investigate preferences for shared decision making, we used two questions adapted from the classic study by Strull et al. (1984). This method has been used often in previous research (Cassileth et al., 1980; Deber, Kraetschmer, & Irvine, 1996; Degner et al., 1997; Degner & Sloan, 1992). The first question asked about the usual role participants play in their interactions with medical doctors. The second asked about the role they believe they should play. Both used a 5-point scale ranging from "1-doctor makes [should make] the decision" to "5-I [should] make the decision." Higher scores meant more active involvement. The questions were pre-

sented on separate pages, and the order of the questions was counterbalanced. Numeracy was measured as described above.

The questions were translated into German by a native German speaker with excellent knowledge of English, back-translated into English by another person of equivalent language skills, and compared with the original English version. Any inconsistencies were resolved by a native German speaker and an excellent English speaker familiar with the research objectives. Finally, the English and the German versions were compared and edited by a bilingual German and English speaker. When programming the questionnaire, special care was taken that the interface looked the same in the two versions. In sum, we believe that the English and German materials were comparable. The Ethics Committee of the Max Planck Institute for Human Development approved the methodology, and all participants consented to participation through an online consent form at the beginning of the survey.

Data Analysis

We classified participants into three groups by their role in decision making: passive, collaborative, and active (see Degner, Sloan, & Venkatesh, 1997, for a similar procedure). For the usual role, participants who answered that their doctor makes decisions for them, or that their doctor makes decisions but strongly considers their opinion (answers 1 or 2 on the 5-point scale) were classified as *passive*; participants who said that they make decisions together with their doctor (answer 3) were classified as *collaborative*; and participants who answered that they make decisions for themselves, or that they make decisions but strongly consider their doctor's opinion (answers 4 and 5) were classified as *active*. The answers to the question about the preferred role were classified in an equivalent way. To calculate the difference between the actual and preferred role, we deducted participants' answers to the usual role question from their answers to the question about their preferred role, and then classified the participants as those who (a) would prefer to have a more passive role, (b) were satisfied with their current role, or (c) would prefer a more active role than they usually had. To calculate the difference, we used participants' raw answers given on 5-point scales, although the pattern of results was very similar when we started from the recoded 3-point scales.

To adjust for the discrepancies due to nonresponse, poststratification weights were used to bring the sample structure in terms of sex, age, and education in line with the structure of the general populations of Germany and the United States (in the first wave)

Table 1
Sample Structure

	Germany (<i>n</i> = 260)		United States (<i>n</i> = 238)	
	Low-numeracy group (<i>n</i> = 127)	High-numeracy group (<i>n</i> = 133)	Low-numeracy group (<i>n</i> = 117)	High-numeracy group (<i>n</i> = 121)
Mean numeracy ^a (<i>SD</i>)	37.3 (15.2)	95.5 (6.0)	36.0 (18.1)	90.9 (9.3)
Mean age (<i>SD</i>)	49.9 (11.9)	43.3 (12.1)	44.3 (13.2)	45.1 (11.7)
% Female	60.6	40.2	58.1	45.6
% Low income ^b	36.8	18.0	31.7	16.4

^a Numeracy scores are transformed to a 0- to 100-point scale. ^b Within bottom third of the general population: in the United States this includes participants with household income up to \$30,000; in Germany, up to €18,000.

and with the structure of high- and low-numeracy groups (in the second wave). Standard errors in all analyses were estimated using the Taylor series linearization method for estimating population characteristics from complex sample survey data, by means of SPSS complex sample procedures and SUDAAN (Siller & Tompkins, 2006).

Results

In line with our hypothesis, the usual role of U.S. participants was more active than that of German participants (see Figure 1). Accordingly, in a multinomial logistic regression analysis with numeracy and country predicting the usual role, the odds of Germans reporting being active were 64% lower than the odds for the U.S. participants ($\beta = -.45, p = .035$). Results for the preferred role show a similar pattern (see Figure 2): German participants preferred a passive role more often than the U.S. participants ($\beta = -.49, p = .023$). Numeracy did not have an effect on answers to either one of the questions: None of the differences were reliably larger than zero.

The *group-level* results shown in Figures 1 and 2 may mask a divergence between usual and preferred roles on the individual level. We, therefore, calculated *for each individual* the difference between his or her answers to the two questions. Figure 3 shows the proportion of participants who (a) would prefer to have a more passive role, (b) were satisfied with their current role, or (c) would prefer a more active role than they usually had. In accord with our hypothesis, approximately one third of the low-numeracy people thought they should be more passive than they currently were (see Figure 3). Among the high-numeracy people, only around 10% wanted to be more passive, with a large majority being satisfied with their role. To rule out the possibility that these differences are an artifact of individual differences in starting point (i.e. people whose usual role is already passive are less likely to show a preference toward an even more passive role) we controlled for the usual role, along with numeracy and country, in a multinomial logistic regression analysis. Even after controlling for this baseline, people with low numeracy were still more likely to report a preference for a more passive role than people with high numeracy: Their odds of preferring a more passive role were twice as high as for the high-numeracy people ($\beta = .72, p = .035$). This pattern of results appeared consistently in both countries.

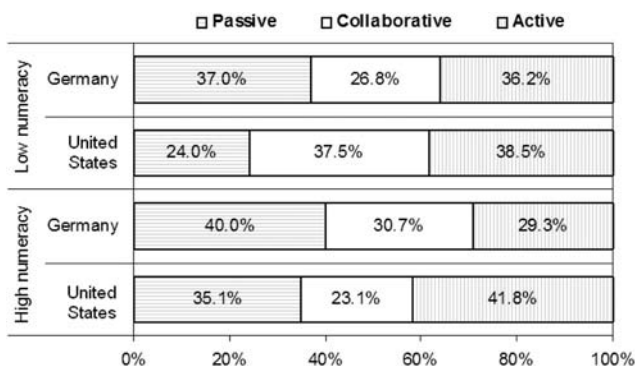


Figure 1. Usual role in decision making by numeracy and country.

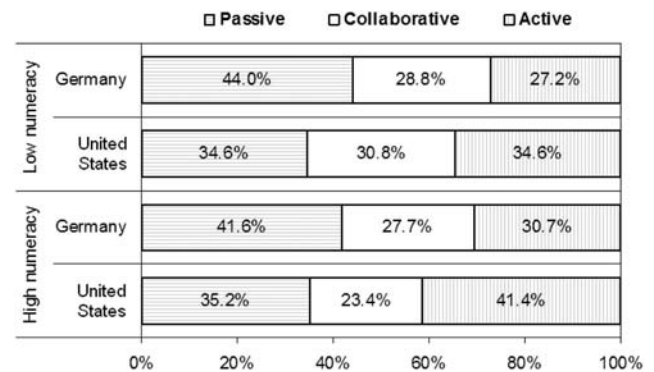


Figure 2. Preferred role in decision making by numeracy and country.

In contrast to the findings of patient-based studies on shared decision making (e.g., Frosch & Kaplan, 1999) and in line with our expectations, our results did not show a negative correlation between age and a preferred role for shared decision making (see Figure 4). On the contrary, in the United States, we found a low preference for active roles in both the youngest (25–39) and oldest (55–69) age groups compared to the middle-aged (40–54) group. This holds for both low- and high-numeracy groups (with the exception of a nonsignificant difference between the two older groups in the high-numeracy group). In Germany, there were no differences between the age groups in either of the numeracy groups. We can then conclude that the relationship between patients' age and preferences for shared decision making is not as straightforward as has been previously suggested.

Discussion

Although we found that a significant number of both high- and low-numeracy people usually play a collaborative or even an active role in decision making about their health, a number of low-numeracy people in both Germany and the United States would prefer to play a more passive role (see Figure 3). This is troublesome given the current trend that encourages patients and

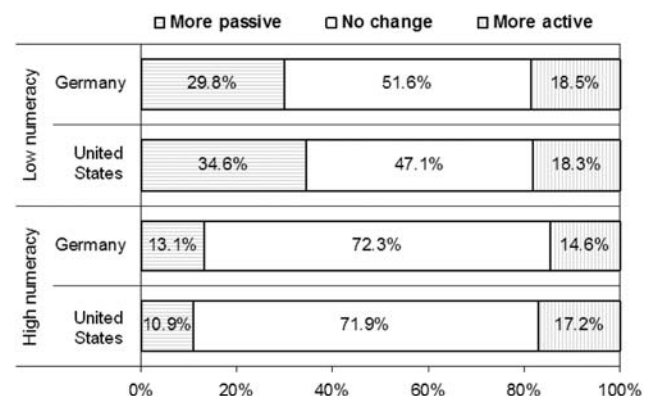


Figure 3. Divergence of usual and preferred role on the individual level by numeracy and country: Percentage of participants who would like to play a more passive role than they usually play, would not like to change the role they usually play, or would like to play a more active role than they usually play.

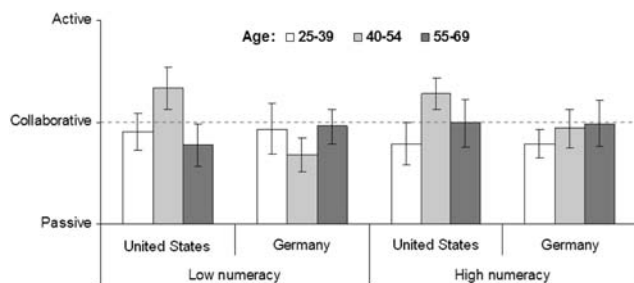


Figure 4. Relationship of age and mean preference for shared decision making by numeracy and country. Bars show means on a 3-point condensed scale (1 = Passive, 2 = Collaborative, 3 = Active). Error bars show ± 1 SE of the means.

doctors to share decision making. It is possible that low-numeracy people do not feel prepared to make important medical decisions without fully understanding information about the risks and benefits of different options (Estrada et al., 2004; Fagerlin, Zikmund-Fisher, & Ubel, 2005; Reyna & Brainerd, 2007; Schwartz et al., 1997). Educational efforts to increase numeracy, as well as the use of communication formats that do not require high levels of numeracy, such as certain graph displays (Galesic et al., 2009; Garcia-Retamero & Galesic, 2010b), metaphors, and analogies (Edwards, 2003; Galesic & Garcia-Retamero, in press) might help low-numeracy patients feel more comfortable as partners in decision making.

The U.S. participants reported a more active role in medical decision making than the German participants (see Figure 1). As mentioned in the introduction, this may reflect differences in the medical systems of the two countries. Interestingly, we did not find evidence for a negative relationship between shared decision making preferences and age (see Figure 4), which is often found in studies on nonprobabilistic patient samples (Cassileth et al., 1980; Degner & Russell, 1988; Ende et al., 1989; Frosch & Kaplan, 1999). Instead, in the United States, we found that both younger and older people preferred to be less involved than the middle-aged group. Younger people in the general population are less likely to have serious illnesses and may, therefore, be less motivated to be involved in decisions about their health.

A limitation of this study is that we only focused on low- and high-numeracy participants. We do not know whether people with intermediate levels of numeracy are more similar to those with a low or high level of this skill. In addition, in these nationwide surveys, we were able to record only participants' reports about their usual and preferred roles in interactions with doctors. We were not able to observe their actual interactions with doctors. However, we feel that the ability to generalize our results to a broader population and to make cross-cultural comparisons compensates for this limitation.

A further limitation of our study is that we have used participants who are members of a survey panel. These participants are regularly invited to give their opinions about a variety of topics, ranging from health issues to terrorism (cf. Baker et al., 2003; Schlenger et al., 2002). It is possible that they are, therefore, different from the general population. In the future, it might be useful to include the questions we asked here in one of the large

national survey studies conducted on cross-sectional samples and compare the results.

Finally, our participants were sampled from a general population and not from a population of patients with immediate medical problems. Therefore, prior experience with doctors may have been minimal for some participants—in particular the younger ones. This could have affected the results, especially the relationship of shared decision-making preferences and age.

This is, to our knowledge, the first study on preferences for shared decision making that uses probabilistic national samples in two countries. We found that numeracy is an important predictor of these preferences, and this finding highlights the need for more patient-centered education efforts and the use of communication formats that do not require high numeracy skills. We encourage further research on the relationship of numeracy skills and shared decision making in general populations of other countries, and in particular, on the ways to overcome negative effects of low numeracy on informed and shared medical decision making in different cultural contexts.

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