# Chapter 13
# On the Effect of Individual Differences on Shared Decision Making*

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**Abstract** 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. In a survey on probabilistic national samples in the USA and Germany, we interviewed participants with low and high numeracy skills. A significant number of people with low numeracy in both the USA and Germany preferred to be more passive than they currently were. High-numeracy people, in contrast, were mostly satisfied with their current role. Education efforts to increase numeracy, as well as using nonquantitative communication formats, may foster involvement of low-numeracy patients in decisions about their health.

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## 13.1 Introduction and Background

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 and 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 and Booth 2007; Caress et al. 2002; Deber 1994; Ende et al. 1989; Gaston and Mitchell 2005; Strull et al. 1984), other studies are less supportive, in particular those involving cancer patients (Degner and Sloan 1992; Frosch and Kaplan 1999). One reason for these mixed results might be that patients' usual role in interactions with medical doctors differs from their preferred role. 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 the study we reported in this chapter 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.

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 and Kaufman 2007; Galesic and Garcia-Retamero 2010; Galesic et al. 2009; Garcia-Retamero and Galesic 2009, 2010b; Nelson et al. 2008; Peters and Levin 2008; Peters et al. 2006). People with low-numeracy skills, for instance, have less accurate perceptions of the risks and benefits of screening and medical treatments (see

Chap. 9; see also Davids et al. 2004; Donelle et al. 2008; Schwartz et al. 1997; Woloshin et al. 1999) and are more susceptible to biases in judgments and decisions than those with high numeracy (see Chaps. 10 and 11; see also Fagerlin et al. 2007; Garcia-Retamero and Galesic 2009, 2010a; Garcia-Retamero et al. 2010; Peters et al. 2006; Reyna and Brainerd 2007, 2008). Therefore, even when patients receive accurate information about all available medical 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 chapter, 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 and Booth 2007; Caress et al. 2002; Deber 1994; Degner and Sloan 1992; Ende et al. 1989; Gaston and 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 et al. 1980; Degner and Russell 1988; Ende et al. 1989; Frosch and 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 and 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 the USA and Germany. As we mentioned (see Chap. 1), most health expenditure in the USA is privately based (55%; World Health Organization 2012), 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 et al. 2005). By contrast, in Germany only 23% of health expenditure is privately based, and most people have health insurance (More than 99%; Statistisches Bundesamt Deutschland 2011). This means that Americans might be more often than Germans required to determine whether they need a medical treatment, and which one would be best given the amount of money they can spend. In addition,

patient-targeted advertising of pharmaceutical products is allowed in the USA but not in Germany, adding to the pressure on US patients to make their own decisions about their health. Because of these differences, we hypothesized that the US 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.

## 13.2 Study: Do Low-Numeracy People Avoid Shared Decision Making?

### *13.2.1 Method*

#### 13.2.1.1 Participants

The study was conducted on probabilistic national samples in the USA and Germany as part of the project "Helping people with low numeracy understand medical information," funded by the Foundation for Informed Medical Decision Making. The project involved a survey that gathered data for a number of studies related to understanding and communicating risks, conducted in two waves (see Chaps. 2, 4, 7 to 11). In the first wave, large national samples of participants ($n = 1{,}009$ in the USA and $n = 1{,}001$ in Germany) completed a numeracy scale consisting of nine items selected from Schwartz et al. (1997) and Lipkus et al. (2001; see Chap. 15). 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 study, resulting in the sample structure given in Table 2.4 in Chap. 2 (see also Chap. 2 for more details about the methodology of the survey). 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.

#### 13.2.1.2 Stimuli and Procedure

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 et al. 1996; Degner and Sloan 1992; Degner et al. 1997a). 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 presented on separate pages, and the order of the questions was counterbalanced. Numeracy was measured as described above.

The questions were developed in English and translated into German (see Chap. 2 for more details about the translation of the materials and the programmed questionnaire). 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.

In data analysis, we classified participants into three groups by their role in decision making: passive, collaborative, and active (see Degner et al. 1997b, 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 were classified as *passive*; participants who said that they make decisions together with their doctor 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 were classified as *active* (see Galesic and Garcia-Retamero 2011). The answers to the question about the preferred role were classified in an equivalent way. To calculate the difference between the usual 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.

### 13.2.2 Results

*What role do people play in medical decision making? How is it related to culture and numeracy?* In line with our hypothesis, the usual role of US participants was more active than that of German participants (see Fig. 13.1). 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 US participants ($\beta$=–0.45, $p$=0.035). Results for the preferred role show a similar pattern (see Fig. 13.2): German participants preferred a passive role more often than the US participants ($\beta$=–0.49, $p$=0.023). Numeracy did not have an effect on answers to either of the questions: None of the differences were reliably larger than zero.

*Does the role people usually play coincide with the role they wish to play in medical decision making? How is this match related to culture and numeracy?* The *group-level* results shown in Figs. 13.1 and 13.2 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. Fig. 13.3 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

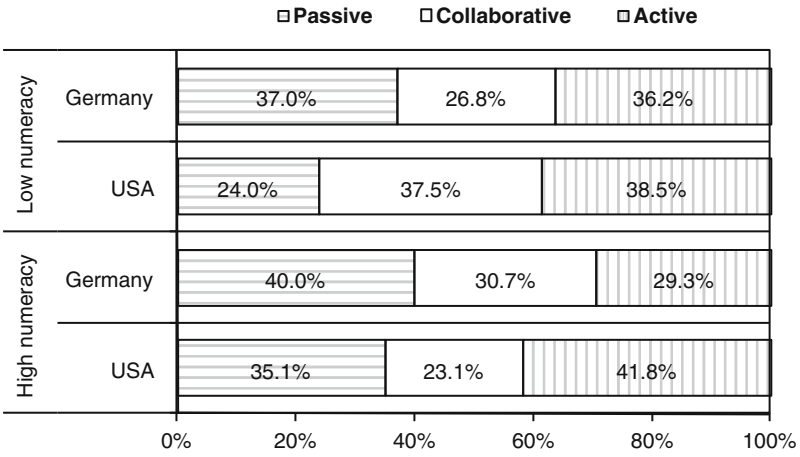


**Fig. 13.1** Usual role in decision making by numeracy and country

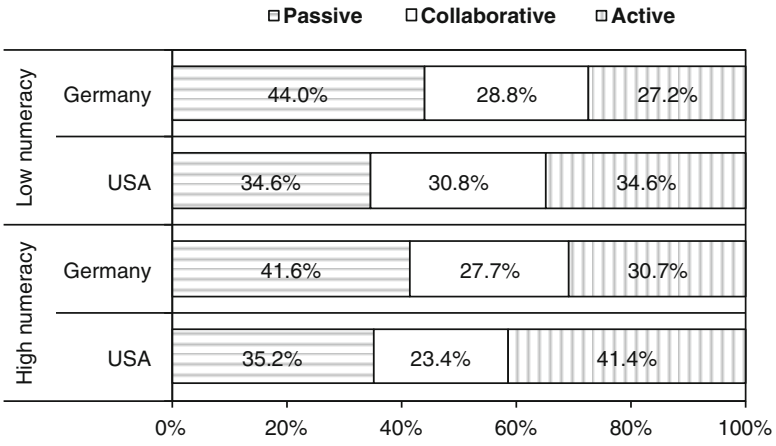


**Fig. 13.2** Preferred role in decision making by numeracy and country

were (see Fig. 13.3). 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 points—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 ($\beta = 0.72$, $p = 0.035$). This pattern of results appeared consistently in both countries.

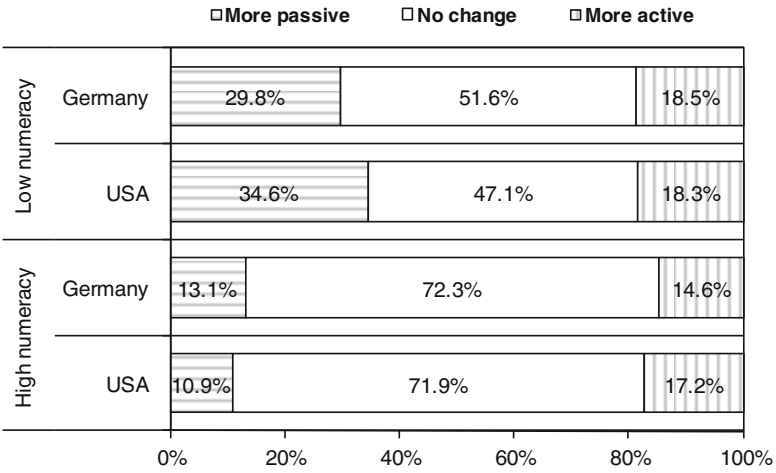


**Fig. 13.3** Divergence of usual and preferred role on the individual level by numeracy and country: Percentage of participants who would like to play a more passive role than they usually play, not to change the role they usually play, or to play a more active role than they usually play

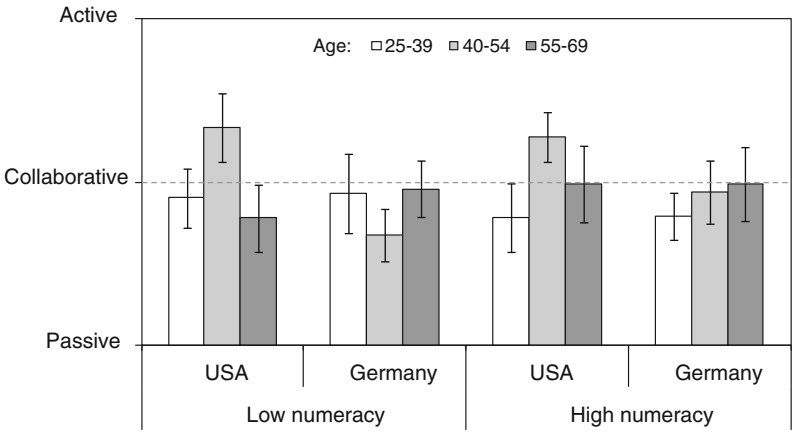


**Fig. 13.4** Relationship of age and mean preference for shared decision making by numeracy and country. *Bars* show means on a 3-point condensed scale (1 = passive, 2 = collaborative, 3 = active). Error bars show ±1 *SE* of the means

*Are preferences for shared decision making related to age?* In contrast to the findings of patient-based studies on shared decision making (e.g., Frosch and 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 Fig. 13.4). On the contrary, in the USA 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.

## 13.3 Discussion and Conclusions

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 the USA and Germany would prefer to play a more passive role (see Fig. 13.3). This is troublesome given the current trend that encourages patients and 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 (see Chap. 2; see also Estrada et al. 2004; Fagerlin et al. 2005; Reyna and Brainerd 2007; Reyna et al. 2009; Schwartz et al. 1997). Education efforts to increase numeracy, as well as the use of communication formats that do not require high levels of numeracy, such as certain graphical displays (see Chaps. 9, 10, and 11; Galesic et al. 2009; Garcia-Retamero and Galesic 2010b), metaphors, and analogies (see Chap. 7; see also Edwards 2003) might help low-numeracy patients feel comfortable as partners in decision making.

The US participants reported a more active role in medical decision making than the German participants (see Fig. 13.1). 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 (Fig. 13.4), which is often found in studies on nonprobabilistic patient samples (Cassileth et al. 1980; Degner and Russell 1988; Ende et al. 1989; Frosch and Kaplan 1999). Instead, in the USA 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 the study we reported in this chapter 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 a 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 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.

The study described in this chapter is, to our knowledge, the first 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, highlighting 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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