How do patients from eastern and western Germany compare with regard to their preferences for shared decision making?

Johannes Hamann1, Christiane Bieber2, Glyn Elwyn3, Eva Wartner4, Elisabeth Hörelin4, Werner Kissling1, Christfried Toegel5, Hendrik Berth5, Klaus Linde5, Antonius Schneider1

1 Klinik und Poliklinik für Psychiatrie und Psychotherapie, Technische Universität München, Germany
2 Klinik für Psychosomatische und Allgemeine Klinische Medizin, Universitätsklinikum Heidelberg, Germany
3 Clinical Epidemiology Interdisciplinary Research Group, Department of Primary Care and Public Health, School of Medicine, Cardiff University
4 Institute of General Practice, Technische Universität München, Germany
5 Salus Institut für Trendforschung und Therapieevaluation in Mental Health, Magdeburg, Germany
6 Medizinische Psychologie und Medizinische Soziologie, Universitätsklinikum Carl Gustav Carus Dresden, Germany

Correspondence: Johannes Hamann, Klinik und Poliklinik für Psychiatrie und Psychotherapie, Technische Universität München, Germany, tel: +49 89 41404282, fax: +49 89 41406688, e-mail: j.hamann@lrz.tum.de

Background: Increasing emphasis is being placed on involving patients in decisions concerning their health. This shift towards more patient engagement by health professionals and towards more desire by patients for participation may be partly based on socio-political factors.

Methods: To compare the preferences for shared decision making of patients from eastern and western Germany we analysed five patient samples (n = 2318) (general practice patients and schizophrenia patients from eastern and western Germany). Patients’ role preferences for shared decisions were measured using the decision-making subscale of the Autonomy Preference Index. Results: Patients resident in eastern Germany expressed lower preferences for shared decision making than patients in western Germany. This was true after controlling for socio-demographic variables and for patient group. Conclusion: The cultural imprint (e.g. western vs. former communist society) seems to have a significant influence on patients’ expectations and behaviour in the medical encounter. Health services providers need to be aware that health attitudes within the same health system might vary for historical and cultural reasons. The engagement of patients in medical decisions might not be susceptible to a ‘one size fits all’ approach; doctors should instead aim to accommodate the individual patient’s desire for autonomy.
Introduction

Increasing emphasis is being placed on involving patients in decisions concerning their health, and there is some evidence that patients express clear preferences for being involved in medical decision making. Patients’ preferences for involvement in medical decision making are often divided into a preference for being informed about the illness and potential treatments (information preferences) and the desire to participate in the actual decision process (participation preferences, often also termed desire for autonomy).

Information preferences are reported to be high in most patients, while there is considerable variability regarding participation preferences.

Participation preferences are considered to have risen in the past decades, based on socio-political factors among others. Movements promoting the rights of citizens, consumers and patients, which have become increasingly active since the 1960s in western countries such as the USA and the UK, are considered to have changed the ‘culture’ of the medical healthcare system. More generally, it is noted that the nature of the encounter is influenced by cultural expectations, e.g. the patients’ and physicians’ role expectations and expectations as to who is involved in decision making.

Since ‘culture’ is a rather broad term, research on this issue ranges from intercultural studies (e.g. focusing on individualistic versus collectivistic culture) to studies focusing on different health care systems or countries. Overall, ‘culture’ is reported to be an important factor explaining differences in patients’ preferences, but results remain inconsistent.

In addition, there is little knowledge about what actually constitutes ‘cultural’ differences, since in previous studies cultural factors (e.g. collectivistic culture) or characteristics of specific health care systems or countries have often interacted with each other.

In the present analysis we aimed to study a specific ‘cultural’ influence on patients’ participation preferences in the medical context, namely the patients’ socio-political imprint. As a measure for this imprint we used the region in which medical care was provided, i.e. whether patients lived in the eastern or western part of Germany.

From 1949 until 1990, Germany had two distinct political systems, with western democracy in West Germany and communism in East Germany. Thus patients living in the two parts of Germany experienced forty years of different political, social and living conditions. People (including patients) in West Germany were probably more influenced by decades of consumerism, which places high value on choice and autonomy. We speculated as to whether living in such a context might lead to patients having higher participation preferences than patients from the former East Germany.

Since the reunification in 1990 the eastern part of Germany has adopted most of the conditions present in the former West Germany, including the health care system. However, 20 years later people living in these areas continue to have different views and attitudes towards the political system, state health and welfare provision, and the role of authority.

In this study our aim was to analyse whether patients currently living in eastern and western Germany differ in their views with respect to their participation preferences in the medical encounter.

Methods

We compared preferences for involvement in medical decision making among patients in eastern and western Germany, for two distinctly different groups of patients. We were therefore able to use data sets from several recent independent surveys, which were pooled for the present analysis:

**GP patients**

From eastern Germany: \( n = 556 \) outpatients from 46 GP practices in Saxony-Anhalt that were involved in a quality improvement project. Inclusion criteria: patients with multiple medications, no other exclusion criteria.

From western Germany: \( n = 1284 \) outpatients \((n = 234\) from four GP practices in the Rhein-Neckar region and \(n = 1050\) from 13 GP practices in the region of Upper Bavaria), no exclusion criteria.

**Schizophrenia patients**

From eastern Germany: \( n = 356 \) inpatients from two psychiatric state hospitals in Saxony-Anhalt. Inclusion criteria: aged 18–65 years, diagnosis of schizophrenia or schizoaffective disorder according to ICD 10. Exclusion criteria: poor German language skills.

From western Germany: \( n = 122 \) inpatients from one psychiatric state hospital and one psychiatric department of a university hospital in Munich. Inclusion criteria: aged 18–65, diagnosis of schizophrenia or schizoaffective disorder according to ICD 10. Exclusion criteria: poor German language skills.

Data for these samples were separately gathered during recent studies on shared decision making, surveys on patients’ participation preferences, or within quality improvement projects in the years 2003–05. In the original surveys, all patients who attended their general practitioner or were admitted to the participating psychiatric wards were consecutively asked to participate. Data on patients refusing to participate were documented only for the GP samples from western Germany (response rate 65–82%, patients not participating were significantly older than patients participating) and the schizophrenia sample in western Germany (28% of patients refusing to participate).

It was not possible to collect data from non-responder patients in eastern Germany.

For all patients, socio-demographic data were recorded (age, gender, education); all patients filled in the Autonomy Preference Index (API) Questionnaire.

The API measures patients’ preferences for two dimensions of autonomy: the preference to be involved in decision-making (decision-making subscale = participation preferences) and the preference to receive comprehensive information (information seeking subscale = information preferences). We applied the decision-making subscale of the API to all patient groups. This self report instrument is designed to measure patients’ general desire to make medical decisions. The decision-making subscale consists of six items (e.g. ‘important medical decisions should be made by the doctor, not by you’) that are measured by 5-point Likert scales. The information seeking subscale was applied to the general practice groups. This scale has eight items which are also measured by 5-point Likert scales. Sum scores were transformed to the range from 0 to 100, where 0 corresponded to very low participation/information preference and 100 corresponded to the strongest participation/information preference. Intermediate scores have been interpreted as reflecting a preference for decision-making to be shared equally between doctor and patient.

Good psychometrical properties have been reported for the API. A German version was established in 2004. Validation studies have reported satisfying psychometric properties for the latter version of the API, with Cronbach’s alpha ranging from 0.57 to 0.85. For organizational reasons, the questionnaires for the schizophrenia patients comprised no information preference scales.

Statistical analysis

Separately for the two medical disciplines, we compared patients’ socio-demographic data and their preferences as measured with the API using \( t \)-tests for the decision-making subscale (normally distributed) and the Mann–Whitney U-test for the information-seeking subscale (non-normally distributed). A \( \chi^2 \)-test was used to compare the binary variables gender and education.

To test our hypothesis (higher participation preferences in western Germany), and since there were socio-demographic differences between
the samples from eastern and western Germany, we performed a hierarchical linear regression analysis with the decision-making subscale (=participation preferences) as dependent variable and age, gender, education, setting (=GP/schizophrenia) (block 1) and east/west (block 2) as independent variables.

**Results**

A total of $n = 2318$ patients were included in the analysis. Patients from western Germany (GP patients and those with a diagnosis of schizophrenia) exhibited higher participation preferences than patients from eastern Germany (table 1). Information preferences showed little variation, and were consistently high in general practice patients.

Linear regression demonstrated that lower age, female gender and longer education predicted higher participation preferences (table 2). Patients suffering from schizophrenia (who were treated as inpatients) expressed lower participation preferences than the GP patients.

Finally, region of care (former East or West Germany) proved to be an independent predictor: patients from western Germany expressed higher participation preferences than patients from eastern Germany. Including region of care in the regression analysis increased $R^2$ from 0.19 to 0.25 (Cohen's $f = 0.08$, small to medium effect size).24

**Discussion**

Patients in eastern Germany expressed lower participation preferences than patients in western Germany. To our knowledge, this is the first study comparing the participation preferences of patients from east and west, i.e. from regions with very different socio-economic and political contexts. This was true after controlling for socio-demographic variables and for patient groups (GP outpatients, inpatients with schizophrenia). Information preferences showed no difference and were always high in both eastern and western German patients.

Thus >15–20 years after German reunification there are still differences between these two populations in patients’ expectations of their role in the medical encounter. The reasons for this difference in patients’ role preferences (i.e. passive vs. active decision maker) could be explained in many ways.

First, differences in dimensions such as individuality (more emphasis on individuality in western societies) are known to influence patterns of patient–doctor communication.23 Thus West Germans, who were more influenced by decades of consumer activity, may therefore have higher participation preferences in medical decisions. In addition, it was shown in the late 1990s that eastern Germans express greater trust in their physicians,26 which could then explain a greater desire for doctors to make health care decisions.27 This might accord with other findings that eastern Germans express more authoritarian attitudes than western Germans.28

Second, patients’ role expectations may also be influenced by the physician. There is evidence of differences between doctors in eastern and western Germany concerning the nature of ‘right’ treatment29 and the ‘right’ patient role.30 In summary, physicians in the east have more paternalistic attitudes towards patients. These data are mirrored by a recent telephone survey showing that patients from Poland, another post-communist country, view their doctors as more paternalistic than patients in most western European countries.13 Thus, patients in eastern Germany who have experienced more paternalistic doctors consequently expect a more passive role.

A possible third explanation is that the density of physicians is lower in eastern than in western Germany, which means that physicians have to care for a greater number of patients, resulting in higher workloads and perhaps less willingness to accommodate innovations such as shared decision making into their work.2

In accordance with Nolte31 our results show in conclusion that we still have much to learn about the health impact of German unification. Our data illustrated for the first time the (still existing) differences in participation preferences of patients in eastern and western Germany. What

---

**Table 1** Socio-demographic characteristics and participation/information preferences of the patient samples from eastern and western Germany

<table>
<thead>
<tr>
<th></th>
<th>GP patients east</th>
<th>GP patients west</th>
<th>P-value</th>
<th>Test</th>
<th>Schizophrenia patients east</th>
<th>Schizophrenia patients west</th>
<th>P-value</th>
<th>Test</th>
</tr>
</thead>
<tbody>
<tr>
<td>n</td>
<td>556</td>
<td>1284</td>
<td></td>
<td></td>
<td>356</td>
<td>122</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age, mean (SD) (years)</td>
<td>67.6 (10.0)</td>
<td>48.1 (17.6)</td>
<td>&lt;0.01</td>
<td>t-test</td>
<td>42.4 (12.7)</td>
<td>37.8 (12.1)</td>
<td>&lt;0.01</td>
<td>t-test</td>
</tr>
<tr>
<td>Gender (female) (%)</td>
<td>54</td>
<td>58</td>
<td>0.07</td>
<td>$\chi^2$-test</td>
<td>55</td>
<td>49</td>
<td>0.29</td>
<td>$\chi^2$-test</td>
</tr>
<tr>
<td>Education (&lt;10 years)</td>
<td>34</td>
<td>64</td>
<td>&lt;0.01</td>
<td>$\chi^2$-test</td>
<td>60.0 (1.2)</td>
<td>5.2 (0.8)</td>
<td>&lt;0.01</td>
<td>t-test</td>
</tr>
<tr>
<td>Severity of the illness (CGI), mean (SD)</td>
<td>–</td>
<td>–</td>
<td>–</td>
<td>–</td>
<td>–</td>
<td>–</td>
<td>–</td>
<td>–</td>
</tr>
<tr>
<td>Participation preferences (API decision-making subscale), mean (SD)</td>
<td>31.2 (13.0)</td>
<td>47.1 (18.7)</td>
<td>&lt;0.01</td>
<td>t-test</td>
<td>34.2 (16.5)</td>
<td>47.1 (17.7)</td>
<td>&lt;0.01</td>
<td>t-test</td>
</tr>
<tr>
<td>Information preferences (API information seeking subscale), mean (SD)</td>
<td>92.02 (8.16)</td>
<td>91.7 (8.31)</td>
<td>0.874</td>
<td>Mann–Whitney</td>
<td>–</td>
<td>–</td>
<td>–</td>
<td>–</td>
</tr>
</tbody>
</table>

**Table 2** Regression analysis (hierarchical linear regression) regarding predictors for patients’ participation preferences (dependent variable: sum score of the decision-making subscale of the API)

<table>
<thead>
<tr>
<th></th>
<th>B</th>
<th>95% CI</th>
<th>P-value</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Block 1 ($R^2 = 0.19$)</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age</td>
<td>−0.43</td>
<td>−0.49</td>
<td>−0.36</td>
</tr>
<tr>
<td>Gender</td>
<td>2.60</td>
<td>0.66</td>
<td>4.53</td>
</tr>
<tr>
<td>Education (&lt;10 years vs. ≥10 years)</td>
<td>3.00</td>
<td>0.98</td>
<td>5.01</td>
</tr>
<tr>
<td>GP patients vs. schizophrenia inpatients</td>
<td>−5.28</td>
<td>−7.87</td>
<td>−2.68</td>
</tr>
<tr>
<td><strong>Block 2 ($R^2 = 0.25$)</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age</td>
<td>−0.24</td>
<td>−0.31</td>
<td>−0.16</td>
</tr>
<tr>
<td>Gender</td>
<td>2.05</td>
<td>0.19</td>
<td>3.92</td>
</tr>
<tr>
<td>Education (&lt;10 years vs. ≥10 years)</td>
<td>3.39</td>
<td>1.46</td>
<td>5.33</td>
</tr>
<tr>
<td>GP patients vs. schizophrenia inpatients</td>
<td>−3.64</td>
<td>−6.16</td>
<td>−1.11</td>
</tr>
<tr>
<td>Eastern vs. western Germany</td>
<td>11.01</td>
<td>8.59</td>
<td>13.43</td>
</tr>
</tbody>
</table>
makes these results especially interesting is that we showed comparable patterns of east–west differences for two distinctly different groups of patients. Patients in general practice are free to choose their physician and can easily change their GP in case of dissatisfaction. In contrast, inpatients with schizophrenia are younger and in many cases admitted against their will or with pressure from their psychiatrists or relatives. In addition, patients with schizophrenia in most cases cannot choose where they are admitted, due to fixed catchment areas of psychiatric hospitals. Thus if these two groups behave similarly this might suggest that our results are transferrable to many other medical fields.

Our analysis has several limitations. First, our data result from separately gathered patient samples. Thus some sort of selection bias might have affected the results. For example, in the GP practices of eastern Germany only patients using multiple medications were included. These patients might suffer from more chronic diseases which might affect their participation preferences. Some studies have shown that participation preferences are lower with chronic diseases. However, another comparison between acute and chronic conditions showed inconclusive results. In addition, non-participating patients in the western GP samples were significantly older than participating patients. Unfortunately, it was not possible to collect data on non-responders from the other samples, but selection effects might have been similar.

Second, while we were able to control for age, gender and education, we could not control for socio-economic status of patients. Since there may have been differences between the samples from eastern and western Germany (e.g. a higher rate of unemployment in the east), the differences detected might partly be a result of economic, and not merely cultural, diversity. Thus the differences found may in part relate less to east/west cultural differences than to other regional specifics such as wealth, unemployment rates or other more localized differences.

Third, our samples were characterized by patients’ current locus of care, not their locus of origin. Thus, some migration effects (from east to west) might have influenced the results, and the differences found may therefore be an underestimation of the true effect.

Finally, the schizophrenic patients had no opportunity to fill in the information-seeking subscale of the API. However, the results of the general practice patients seem to be transferable, as is a well known phenomenon that their information preferences are always high.

Conclusion

Participation preferences, and therefore preferences for different communication styles, might depend on cultural differences between specific regions. Researchers into shared decision-making should more often take cultural diversity into account when performing studies of patient participation. It may take longer than expected to reach a common sense of the necessity for, or prospects of, more patient-centred doctor–patient interaction, as can be seen from the fact that 14–16 years after reunification there are still differences between eastern and western Germany.

It must be emphasized that our results again underscore that, as regards the engagement of patients in medical decisions, a normative ‘one size fits all’ approach to shared decision making might not be the most promising way to meet patients’ participation preferences. Therefore it is suggested that doctors should find ways to match the individual patient’s desire for autonomy. According to our results, cultural aspects of the patient and his or her environment should also be taken into account.

Conflicts of interest: None declared.

Key points

- Patients’ participation preferences might depend on cultural differences between specific regions.
- As regards the engagement of patients in medical decisions, a normative ‘one size fits all’ approach might not be the most promising way to meet patients’ participation preferences.

References


If patient empowerment and enhancement of autonomous decision making is seen as an ethical principle, its implementation needs to be performed and studied across cultures.
Perceived discrimination outside health care settings and health care utilization of Turkish and Moroccan GP patients in the Netherlands

Majda Lamkaddem1,2, Marie-Louise Essink-Bot2, Walter Devillé1,3, Marleen Foets4, Karien Stronks2

1 NIVEL (Netherlands Institute for Health Services Research), Utrecht, the Netherlands
2 Department of Public Health, University of Amsterdam, the Netherlands
3 Medical Anthropology and Sociology Unit, University of Amsterdam, the Netherlands
4 IBMG (Institute of Health Policy and Management), Erasmus University, Rotterdam, the Netherlands

Correspondence: Majda Lamkaddem, AMC/UVA, PO Box 22660, 1100DD Amsterdam, The Netherlands, tel: +31 20 566 7443, fax: +31 20 697 2316, e-mail: m.lamkaddem@amc.uva.nl

**Background:** Problematic interethic relationships, expressed by feelings of discrimination, may contribute to ethnic variations in health and health care utilization. The impact of daily perceived discrimination on (mental) health has been shown. Less is known about the effect of everyday discrimination on the health care utilization. We examined the relationship between perceived discrimination of Turkish and Moroccan patients on GP health care utilization in the Netherlands and on health services use in the home country. **Methods:** Cohort study within the second Dutch National Survey of General Practice (2001). Interviews were conducted with 416 Turkish and 381 Moroccan respondents, and repeated in 2005 among respectively 118 and 102 participants. Linear, logistic and zero-inflated binomial regression models were used for the analyses. **Results:** Perceived discrimination was associated with non-attendance to the GP. Perceived quality of GP care was not a mediator in this relationship. No evidence was found for substitution of health care utilization in the home country to health care in the host country. GP attenders had higher odds of using health care in the home country than non-attenders. Over time, a lasting discrimination feeling was related to persistent non-attendance at the GP practice. **Conclusion:** Ethnic minority patients who feel discriminated may avoid GP health care. Further research is warranted on magnitude and health effects of such potential underutilization. Information on perceived discrimination within health care settings would increase insight into the profile of non-attenders, and on possible measures to better target interventions at a group at risk of underutilization.

**Introduction**

An extensive body of literature shows that perceived discrimination is associated with health problems, including depressive symptoms, psychiatric disorders, and general poor self-rated health. Perceived discrimination has also been studied for its impact on health behaviours. Studies addressing this link found that perceived discrimination is associated with underutilization of care in general, medical care delays and non-adherence to treatment, pharmacy prescription delays and medical tests delays, or substituting alternative health care to conventional health care. The association between perceived discrimination within health care settings and underutilization is easily understandable, in situations where patients avoid disagreeable medical encounters. However, the relation between perceived discrimination outside health care settings and underutilization of health care is less easy to explain. Studies focusing on underlying mechanisms are scarce. Some answers were formulated, for which empirical testing lacks until now. Burgess found evidence for an independent effect of perceived discrimination outside health care settings on health care underutilization, and suggested that experiences of perceived discrimination outside health care settings might lead individuals to avoid dominant culture institutions. These include the health care system, in which discrimination might occur as well. The first objective of this article is to specify the explanation proposed by Burgess and test it empirically. When seen as potentially stressful, we expect the perceived quality of medical encounters to decrease in the eye of the patient. Perez et al. found an association between perceived discrimination outside health care settings and perceived quality of care. Perceived impaired quality of care would, in turn, affect utilization of health care. The effect of perceived discrimination outside health care settings on health care utilization would therefore be mediated by perceived quality of care. Perceived discrimination may also have consequences for health care seeking behaviour. Bazargan showed that discrimination feelings are strongly related to alternative health care use. Would the use of health care in the country of origin constitute an alternative to mainstream healthcare in the host country for immigrants? In the Netherlands, it is common for some immigrant groups to spend holidays in the countries...