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Abstracts

The German health care sector 2001–2015 from the perspective of the insured
Gerd Marstedt, Hartmut Reiners

Keywords: health care sector, reforms, reform needs, reform legislation, health care system, health care reform, solidarity principle, care quality, medical care, health care, public opinion, statutory health insurance

Summary
“After the reform, more reform” – this formulation quite accurately describes the long series of diverse health care reforms introduced since the Health Care Reform Act of 1988. Against this background, this article addresses how the general population has perceived and assessed these changes to the health care system, which have often been confusing for laypeople. The focus is on the solidarity principle in the statutory health care system, the degree of satisfaction with medical care, and anxieties regarding future developments, among other topics. Overall, from 2001 to 2015, judgments regarding reform needs in the health care sector and the population’s degree of satisfaction with health care both showed a very substantial temporal stability. However, clear differences between population groups are at times evident, with younger generations rendering opinions that are markedly more critical.

Background and inquiry
In the 2001–2015 period, numerous health care reforms with notable consequences for insured persons and patients were adopted. The
question is whether and how these reforms have been reflected in the opinions of the insured. The study also examines whether there are significant differences between population groups (such as the healthy and the chronically ill, or those with statutory and private health insurance) in the evaluation of care structures and financing modalities in the health care sector. Finally, it investigates whether popular trends in opinions regarding the health care system are linked with general value orientations and knowledge levels, and thus whether knowledge about patient rights or general moral positions also influence opinions regarding the statutory health care insurance system or care quality.

Methods
The analysis is based on a total of 23 Gesundheitsmonitor surveys from the years 2001 through 2015, all based on representative population samples of respondents from the ages of 18 to 79. The samples each contain about 1,500 to 1,800 respondents. Data from multiple survey waves were in some cases combined. A variety of methods were used for the analyses, including crosstabulations with significance tests of changes over time, correlations, and multivariate analyses (logistic regression).

Findings
The variety of reform legislation approved since 2001 stands in striking contrast to the stability of the assessments rendered by the insured, which consistently document a high level of satisfaction with health care and the structures of the health care system. However, there are also points of criticism that center on a lack of reform efforts on the service-provision side. Moreover, there is considerable anxiety with regard to the potential for future deteriorations, for instance through rationing, a limitation of services, or waiting times.

The analyses do not show evidence of systematic disadvantages faced by the chronically ill or disabled with regard to health care. However, it is clear that the acutely ill hold greater fears and render more critical judgements – a sign that patient- and insured-population assessments of health- and care-oriented issues are inevitably permeated by fears and sensitivities. In addition, a significant, nearly universal discrepancy in the analyses appears between young and old people with regard to evaluations of the health care system and opinions on
care and financing structures: Younger people are consistently both more critical and more worried.

An additional relevant finding of the analyses shows that those demonstrating minimal or even a total lack of knowledge about the health care system or individual patient rights tend to engage in sharper criticism of precisely these regulations and standards.

**Conclusions**
The fact that minimal or even a total lack of knowledge about the health care system or individual patient rights is associated with sharper criticism of these regulations and standards shows significant opportunity for improvement with regard to authorities' information strategies regarding patient rights and care structures. In this regard, greater attention should be paid to young people's reading and information-gathering habits. In general, future-oriented questions regarding treatment and care quality should be brought more strongly into the foreground of health care policy. This trend has already shown itself in the approaches taken by laws adopted in the fall of 2015, such as the second Act to Strengthen Long-Term Care (Pflegestärkungsgesetz II) and its new definition of the need for long-term care oriented toward quality of life, as well as in the Statutory Health Insurance Care Improvement Act’s (GKV-Versorgungsstärkungsgesetz) regulations reducing waiting times, and the Hospital Structure Act’s (Krankenhausstrukturgesetz) promotion of quality standards. The idea that financial incentives and more competition are sufficient to regulate issues of care quality – a conception that has dominated health care policymaking in recent years – falls short.

**Published in**
Primary care in flux?
*Melanie Schnee*

**Keywords:** primary care, steering function, consultation fee, chronically ill

**Summary**
The promotion of primary care has long been on the political agenda. This article examines whether an intensified utilization of primary-care functions (general practitioner as first point of contact, long-term care by a general practitioner, coordination with secondary and tertiary care, and the provision of comprehensive psychosocial and preventive care) can be observed within the Gesundheitsmonitor’s observation period. In addition, it investigates whether the social and health status of primary care users has changed.

**Background and inquiry**
One of the first political reforms aimed at strengthening general practitioners and so-called primary care was the Health Care Structure Reform Act (Gesundheitsstrukturgesetz, GSG), which among other changes prevented the expansion of specialist technical medical services, and was intended to promote narrative-based medicine. With regard to the doctors themselves, this took place primarily through a new edition of the Uniform Fee Schedule used within the statutory health insurance system. During the Gesundheitsmonitor observation period, various reforms aimed at strengthening the primary-care functions on the part of the insured population and insurance providers were carried out, including the introduction of consultation fees as a means of strengthening practitioners’ steering and coordination function, general practitioner care models, and disease-management programs aimed at bolstering long-term and comprehensive care.

Access to primary and specialist medical care holds a prominent position within the above-noted functions, as the other functions – that is, the ability to coordinate care, and the provision of long-term and comprehensive care in all areas – can only emerge once this is more restrictively regulated. The abolition of consultation fees represents a reversal of the previous political strategy. The overarching question to be examined in this paper is: Given all the changes in the care environment, has anything in fact changed for patients and
primary-care physicians? Or, in the wake of the health care policy efforts of the last years and decades, particularly with regard to strengthening primary care, has the desired result finally been achieved: that patients are increasingly using these primary-care functions?

Methods
The individual Gesundheitsmonitor survey waves were paired into “annual waves,” each with about 3,000 respondents. A descriptive time comparison across all Gesundheitsmonitor insured-population survey waves from 2001 through 2015 was then performed. Logistic regressions were used as an analytical method to classify users of the various dimensions of primary care at the beginning (2001/2002) and the end (2014/2015) of the observation period.

Findings
More than 90 percent of the insured have a primary care physician, and three out of four respondents have been under this doctor’s care for more than five years. No great changes are evident in the 2001 – 2015 observation period with regard to the duration of care, or the nature of psychosocial and preventive care provided. The steering and coordination function was significantly strengthened by the introduction of the consultation fees. The share of respondents who say the reason for their most recent visit of a primary-care doctor was to pick up a letter of referral climbs from 18 percent at the start of the period to an average of 40 percent, and declines in the years after the discontinuation of the consultation fee to a value of around 24 percent. The current users of referral letters are primarily respondents more likely to be affected by comparatively serious, multiple or chronic diseases. The chronically ill are integrated more deeply into the primary-care system at the end of the observation period than at the beginning.

Conclusions
Both the descriptive time comparison and the multivariate analyses show that the primary care system is functioning reasonably well, in the sense of fulfilling functions such as the coordination with other care areas, the durability of relationships between the general practitioner and the patient, and the provision of comprehensive psychosocial and preventive care. The consultation fee had a positive effect with regard to strengthening the primary-care physician’s steering and
coordination function. Its discontinuation reverses effects reached up to that point. However, at the end of the observation period, the primary-care functions are still used especially by those who have a particular need for primary care. This could be due to a greater appreciation of continuous care of the chronically ill by a primary-care physician, as this can be particularly influenced by the introduction of general practitioner care models and disease management programs.

Published in
Undersupply in rural areas – Perceptions of the insured and their preferences for innovative care models
Laura Schang, Wiebke Schüttig, Leonie Sundmacher

Keywords: needs planning, undersupply, oversupply, survey of insured population, health care models

Summary
Needs planning in Germany’s outpatient sector has primarily been aimed at limiting the number of contract physicians, and is increasingly criticized as being too rigid, imprecise and out of date. The shortage of doctors in rural areas and the unequal regional distribution of contract doctors have become points of public discussion. Reform of the needs-planning process through the Care Structure Act in late 2011 and through the work of the Federal Joint Committee has sought to create more regional flexibility to use innovative models to overcome the physician shortage and to better reflect existing care needs. This paper examines the preferences of the rural population with regard to close-to-home medical care in order to obtain information for needs-planning reforms.

Background and inquiry
The allocation scheme defines “normal care” in a planning region (usually a district or independent city) on the basis of the actual number of doctors as of December 31, 1990. Because a significant share of patients at the regional level travel between the city and surrounding areas for care, every region was categorized into one of five regional types based on the density of its commuting ties. However, the regional types in some cases differ strongly with regard to their balances of inward and outward commuters. Various models aimed at ensuring care in rural areas have been proposed and brought to the pilot stage. However, several promising strategies, such as the creation of a transport service for patients in Brandenburg, were later discontinued due to a lack of demand. The actual preferences of the insured have to this point been unclear.

The following main questions are examined:
– What urban-rural disparities exist with regard to perceptions of an undersupply of doctors in various specialties?
– What expectations do rural residents have with regard to close-to-home medical care, as compared to those in urban spaces?
What care models do residents of underserved areas prefer (with the exception of fully occupied physician practices)?

Methods
The 2015 Gesundheitsmonitor survey of the insured population provides representative data on 1,598 insured persons in Germany. In order to compare the insured population’s perceptions of undersupply with the actual density of physicians, structural data published by the Central Research Institute of Ambulatory Health Care in Germany (ZI) was also used.

Findings
Across specialties, more of the insured in rural areas than in urban areas report an undersupply (particularly of dermatologists, ophthalmologists and orthopedic surgeons). As the density of physicians at the regional level rises, the share of residents reporting an undersupply of physicians in the respective specialty tends to decline. Nevertheless, even in the regions with the nation’s highest physician density, 15 percent to 30 percent of the insured perceive an undersupply. In planning districts where physician densities are (nearly) the same, more insured persons in rural areas than in the city perceive an undersupply of doctors.

Having care close to their place of residence is of key importance for nearly three-quarters (74%) of employed respondents. Around 5 percent prefer to have outpatient medical care close to their workplace. About one-fifth (21%) have no preference between the two. In the distribution of these preferences, there is no difference between the insured in urban and rural areas. Acceptance rates were highest for outpatient treatment at a hospital or on certain days of the week at a group-practice facility on certain days of the week, respectively at 57 percent and 55 percent. Public acceptance was lowest for a transport service (27%) and contact by telephone, video consultation, or email (24%).

Conclusions
There are notable urban-rural disparities in the perception of doctor shortages. An increasing physician density is associated with a lower share of insured persons who perceive a condition of undersupply in that area. Nevertheless, even in those areas that, from a needs-plan-
ning perspective, have an oversupply, there is a clear perception of undersupply. Additional instruments such as a more precise needs index are necessary in order to refine the regional planning process. Urban-rural disparities in subjective perceptions of shortages under conditions of objectively equal physician density might be explained by the fact that doctors in rural regions are more geographically dispersed than those in the city. This could indicate that the regional level is too large to serve as an effective planning area.

Nearly three-quarters of the employed prefer care close to home over care close to their workplaces. These preferences should be taken into account when using the commuter-balance indicator to measure the effect of patients crossing between urban and rural regions to obtain care. Otherwise, needs-planning ratios based on these indicators run the risk of perpetuating urban areas’ historically contingent higher physician ratios. Innovative care models are accepted by the population to different degrees. Targeted public-relations work is necessary in order to help the population understand what alternatives are available.

Published in
Knowledge and perception of patient rights in Germany 2010–2015
Sebastian Euler, Jan Böcken

Keywords: Patient Rights Act (PatRG), patient rights, citizen survey, patient knowledge, doctor-patient communication, patient records, informed patients

Summary
In comparison to 2010, citizens in Germany five years later (2015) believe they are better informed about their rights as patients; in fact, however, their knowledge on this topic has diminished. In addition, there are fewer citizens in 2015 who express reservations in exercising their rights as patients. In 2015, “informed patients” with regard to patient rights come as expected from higher income and educational levels. In order to make citizens’ growing desire for more participation in the doctor’s consulting room practical, actors in the German health care sector have the duty to provide better information on patients’ rights.

Background and inquiry
Since early 2013, the Patient Rights Act (PatRG) has combined the most important patient rights into a single law, with the aim of promoting cooperation between patients and doctors during treatment. This article examines how the population’s knowledge and perception of their rights as patients has changed in 2015 in comparison to the first survey addressing this issue. It also characterizes the sociodemographic and personal attitudinal characteristics of 2015’s informed patient with respect to patient rights.

Methods
The Gesundheitsmonitor survey waves used for the analyses (No. 17, from 2010, n=1,789; No. 23, from 2015, n=1,598) are representative of the German population between 18 and 79 years of age with regard to sex, federal state, age, income and education. Weighted analyses were performed in order to increase the comparability of the two data sets. The findings are based on frequency studies as well as bivariate and multivariate analyses.
Findings
Survey respondents’ actual knowledge regarding their rights as patients has decreased slightly between 2010 and 2015; for example, in 2015, one-third of respondents were not aware of their right to view their personal patient records (as compared to one-fourth of respondents in 2010). By contrast, 28 percent now assess their knowledge regarding patient rights as being “very good” or “good” (2010: 21%), and only 23 percent assess it as “satisfactory” or “unsatisfactory” (2010: 30%). The gap between actual levels of knowledge and subjective assessments of knowledge on patient rights has thus grown between 2010 and 2015.

At the same time, respondents’ self-confidence in exercising their patient rights has risen surprisingly since 2010. In 2015, respondents with strong subjective confidence in their patient-rights knowledge are nearly twice as often of the opinion that exercise of their patient rights does not negatively influence the quality of their medical care (2010: odds ratio=2.6; 2015: odds ratio=4.8).

The informed patient with regard to patient rights in 2015 socio-demographically tends to come from a higher education and income level, often suffers from a long-term illness, and tends to be (or have been) employed in the health care sector. With regard to attitude, he or she wants to meet the doctor on an equal footing, and have a say in planning his or her treatment. In addition, this type of patient has less fear than do less well-informed patients of possible negative consequences to the exercise of his or her patient rights.

Conclusions
One explanation for the opposing trends in citizens’ actual and self-assessed knowledge about patient rights could be that news coverage of the Patient Rights Act in 2012/2013 subconsciously led the population to take a more self-confident stance on this issue. However, for citizens to be able to carry out their growing desire for more participation in the doctor’s consulting room, the force of a single law is not enough; rather, all actors in the health care sector have the duty to reverse the negative trend with regard to knowledge of patient rights. For those population groups comfortable online, the Internet offers opportunities to provide better information than in the past to target groups that may otherwise be difficult to reach. In a hopeful development, those at the lowest income and education levels have particu-
larly gained in self-confidence over the 2010–2015 period, and thus could be more easily reached and more receptive to broader informational activities than previously. In addition to the patients themselves, doctors too must become even more aware of patient rights and the associated opportunities.

**Published in**
The electronic health card – Knowledge, acceptance and expectations in the general population
Sophia Gottschall, Susanne Mauersberg, Timo Thranberend, Kai Helge Vogel

Keywords: electronic health card (eGK), health card, insurance card, citizen perspective, digitization, networking, integrated care

Summary
The electronic health card (eGK) represents one of the most important reform projects in the German health care sector. Thanks to unresolved conflicts between interest groups, its introduction has been continuously delayed in recent years. The card has now been introduced across the country since January 2015. However, citizen's perspectives have played hardly any part in the discussion over the project’s establishment. To be sure, while citizens are accorded a central, “active role” with regard to the electronic health card, acceptance of the card is necessary for this role – not least because the so-called opt-in rule means the health card's success will rise and fall with citizens’ readiness to adopt it.

Background and inquiry
In view of the special role given to citizens within the electronic health-card project, the survey results should make a contribution to closing gaps in knowledge regarding the citizen perspective. The findings should show how popular acceptance of the card and its uses within the insured population have developed and will continue to develop. The article focuses on the following questions:
- What knowledge does the population have regarding the characteristics of the electronic health card?
- What expectations do citizens express with regard to the provision of information about the health card?
- What are the population’s security needs with regard to the electronic health card?
- What benefits do the population expect from the electronic health card?
- To what degree is the health card accepted with regard to the storing of data and access by different occupational groups?
- What expectations do citizens have with regard to their own role in dealing with the electronic health card?
Methods
As a part of the Gesundheitsmonitor’s 23rd survey wave, conducted in 2015, a total of 1,598 insured persons were given written surveys. The sample is representative of the German population aged 18 to 79 with regard to sex, age and region. Descriptive statistics and logistic regressions are used as analytical methods.

Findings
The survey results show that overall acceptance of the electronic health card has changed little despite the lengthy introduction process. The insured population continues to support the introduction of the card, and hopes that the eGK will bring considerable benefits. However, uncertainty within the insured population has also increased.

With regard to planned applications, added value is seen particularly in the storage of emergency and medication data on the card. Here, a majority of respondents can even imagine general storage of this data without their prior consent. For the storage of electronic patient-record data, however, people by contrast want to be explicitly asked.

With respect to the issue of access rights, citizens very clearly see themselves in the role of decision-makers who want to retain control over the distribution of their data. Patients primarily see doctors and their staff as having authorization to access the information, particularly when it comes to the emergency data. The population is more skeptical than ever on the issue of data security. More than one-third believe that the data accessible through the card is unsafe.

Six out of 10 respondents feel they are insufficiently informed about the electronic health card. When asked about the card’s specific functionality, it is clear that citizens do not have enough knowledge to make a sound judgment. In addition, citizens tend to trust information from health-insurance companies and patients’ and consumers’ organizations more than that from medical associations or politicians.

Eight out of 10 respondents would generally consider using the electronic health card in the future to view their own medical data and documents. For this purpose, a means of access in a protected, trusted space close to home is preferred.
Conclusions

The basic level of acceptance needed for a successful project, at least with regard to citizens, is (still) in place. When asked, citizens recognize the core benefits and the overall objectives of the electronic health card. However, in the short term, more accessible information and clarifications are needed in order to minimize existing and emerging uncertainties. The challenge of convincing skeptics should not be an obstacle to communication, as simply preventing the loss of the fundamentally open-minded will suffice as a communications task. Data security (and data flows), along with information on how data-protection measures, plays a critical role.

The critical function assigned to the insured themselves as a part of the project concept must remain in place, thus enabling them to retain control over their data. Indeed, the electronic health card has the potential to strengthen patients in their role overall, giving them greater autonomy and enabling more participation in their treatment. However, for this to succeed, they must be provided with adequate and usable opportunities to access this data.

Published in
Physicians’ experiences with, attitudes toward and handling of informed patients

Anja Bittner

Keywords: health information, patient counseling, doctor survey

Summary
The Gesundheitsmonitor doctor survey addresses physicians’ experiences with, attitudes toward and handling of informed patients. The point of departure is patients’ increasing tendency to pursue independent research into health issues, as well as the degree to which doctors are comfortable with patients’ attempts to take greater responsibility for their own health.

Background and inquiry
The Gesundheitsmonitor doctor survey carried out in 2015 should help clarify several issues, including the experiences physicians have had with self-informed patients, their views on patients’ independent searches for information, and the character of the advice and information they provide in consequence. The findings were compared in part with the results of a doctor survey from the year 2003. The following questions were examined:
– How have doctors’ attitudes developed toward patients who seek to inform themselves through channels outside of the physician consultation?
– How do doctors handle informed patients?
– How familiar are doctors with information offerings for patients?
  Is the medical field becoming open to patients who are taking responsibility for their own health?

Methods
As an element of the Gesundheitsmonitor 2015 doctor survey, an online survey was conducted among outpatient doctors in the following fields: general medicine, internal medicine, anesthesia, general surgery, gynecology and obstetrics, pediatrics, psychiatry and psychotherapy, neurology and orthopedics, skin and venereal diseases, urology, ophthalmology and ENT medicine. The data analyses are based on 804 online questionnaires. The data have in part been compared with a sample of physicians from the year 2003, through a compara-
tive analyses. Analytical methods included descriptive statistics, correlations and logistic regression.

**Findings**
The survey results show that patients are not only informing themselves with increasing frequency, but also speaking with their doctors about their research findings. In this regard, therapies, symptoms, illnesses in general and health-insurance services lead the list of topics that patients have acquired information about either accidentally or through their own research, and about which they subsequently talk to their doctors.

Doctors show strongly varying evaluations of the effects of this self-directed information gathering. More than half of the respondents take a quite nuanced view of patients’ information searches, and see both positive and negative aspects with respects to the doctor-patient relationship. By contrast, about a quarter of the physicians surveyed evaluated the impact as primarily positive or primarily negative. In this respect, the evaluation is related to patients’ assessed levels of knowledge, the physician’s own degree of familiarity with the health information accessible to laypeople, and the doctor’s professional experience.

In addition, secondary aspects of patients’ efforts to inform themselves, such as the advancement of patients’ own health knowledge, the signaling of a personal interest, or an impact on patient-doctor trust, show considerable disagreement. However, in comparison to a 2003 survey, doctors show a much more significantly negative assessment with regard to the benefits and risks of self-gathered information. Just under a quarter of the doctors even actively dissuade patients from engaging in independent searches for information. At the same time, however, it is clear that doctors’ familiarity with the information sources available to patients often remains insufficient.

**Conclusions**
The increase in informational offerings for patients and the growing interest among lay people in health-related issues remains highly controversial within the medical profession. It is clear in this regard that doctors today assess their patients’ self-directed information searches significantly more negatively than was the case in 2003.

About a quarter of the physicians evaluate the effects of such information searches negatively, while half of the respondents are of two
minds in this regard. Moreover, although a quarter of the physicians evaluated self-directed information searches negatively, only around 11 percent of the respondents question whether their self-informed patient had previously wanted more advice from them.

A significant need for action is also particularly evident with regard to doctors’ familiarity with patient-oriented health information. Their often insufficient degree of knowledge in this area not only results in a miscalculation of the credibility of information offerings, but is also strongly associated with negative evaluations of patients’ self-directed information-search efforts.

A joint effort between doctors, patients and other actors in the health care sector to further consider and develop health information appears to be urgently necessary in order to close existing perspectival gaps between patients’ desires and actions and doctors’ perceptions.

Published in
The use of and demand for second opinions, from the perspective of the general population
Max Geraedts, Rike Kraska

Keywords: second opinions, diseases, operations

Summary
In Germany, the number of certain non-urgent medical procedures and operations for which indications are inconclusive has shown a persistent rise. For this reason, lawmakers recently strengthened the right of the insured to a second medical opinion in the case of commonly ordered, often profitable procedures. The aim is to curb the growth of supposedly unnecessary procedures. However, those with statutory health insurance already had the possibility of obtaining a second opinion. The effect of such second opinions has been the subject of very little research in this country to date.

Background and inquiry
Conducted in 2015, the survey should help clarify the degree to which and the reasons for which citizens seek second opinions; whether there are differences between socioeconomic status groups; what diagnoses or therapeutic procedures lead to or are thought to justify second opinions; and whether second opinions lead to changes in decisions and ultimately to a reduction in genuinely unnecessary procedures.

Methods
To answer these questions, a representative general-population survey was carried under the auspices of the Gesundheitsmonitor, a Bertelsmann Stiftung and BARMER GEK project. The response frequencies were examined using inferential statistical methods, with descriptive and bi- and multivariate analyses, including logistical regression.

Findings
Out of 1,598 respondents, 24 percent had obtained a second opinion, and 32 percent had at least considered doing so. This group included significantly more insured individuals from the former West German federal states, with a poorer health status, and of a comparatively low age. Gender and socioeconomic status played no role in the use of a second opinion.
Many respondents expressed the fundamental desire to be able to seek a second opinion, particularly in the case of cancer diagnoses and prior to surgical procedures. However, among those respondents that had already obtained a second opinion, it appeared that musculo-skeletal system operations, drug therapies and dental diseases, rather than cancer diagnoses, were the leading grounds.

Among the reasons for obtaining a second opinion, three groups could be distinguished: first, a bad experience with previous examinations or treatments, or a lack of trust in the doctor; second, general uncertainty about the decision; and third, a recommendation to do so by another person.

For a majority (72%) of respondents with such experience, second opinions had led to a change in their decision regarding an examination or treatment indicated by the first opinion: 45 percent of respondents agreed that their decision had changed, 26 percent said this was partially accurate, and only 27 percent had not changed their decision.

 Accordingly, nearly all respondents considered obtaining a second opinion to be useful: 74 percent stated it to be definitely useful, and just 5 percent said that a second opinion was either probably or definitely not useful.

Conclusions
The population expresses a high level of demand for second opinions, particularly in the case of uncertainties regarding the treatment of serious diseases. Second opinions are to some extent already performed today, and are deemed relevant and useful in the decision-making process. In order to keep it this way in the future, a patient-oriented, equitable offering open to all social classes should be made available, which is not limited to high-volume procedures. In addition, research work should be promoted that analyzes the outcomes of treatment both with and without second opinions, and thus assesses the effects of such systems in Germany.

Published in
Disc surgery – Patient experiences, indication quality and emergency coding
Matthias Bäuml, Mathias Kifmann, Jonas Krämer, Jonas Schreyögg

Keywords: back pain, disc surgery, indication quality, guidelines, emergency coding

Summary
Based on a survey of the insured population, the article addresses the experiences of patients with intervertebral disc damage in the lumbar vertebral area who received disc surgery. In particular, the quality of the indication is examined. For 29 percent of the respondents whose operations can to the greatest extent possible be understood as non-emergencies, conservative therapies were not consistently followed, or operations were performed even though these therapies were having a positive effect. This is contrary to the guidelines of the German Society of Neurosurgery. In the case of persons who received a prior consultation at the hospital or a second opinion, the share of operations conforming to the guidelines was significantly higher. Strengthening consultations and second opinions could induce more people to pursue conservative therapies. Another approach would be to make conservative therapies more available to employed people and to make their chances of success more salient. In addition, it is evident that there is a significant difference between hospitals’ coding of emergencies and the emergency indicators specified in the survey.

Background and inquiry
The number of people undergoing disc surgery in Germany is increasing. If there are clear signs of an emergency, this operation is certainly indicated. Otherwise, a conservative therapy is initially advised. Economic incentives can lead to a situation in which disc surgeries are performed too frequently. From the patient’s perspective too, a disc operation can appear more attractive than conservative therapies, as a faster recovery is expected.

This article focuses on the issue of whether conservative treatments methods are tried before resorting to disc surgery in non-emergency cases. To this end, patients that received disc surgeries were surveyed. The degree to which hospitals’ coding of cases as emergencies match a set of emergency indicators specified in the survey is also
considered. The background for this question is that the number of cases coded as emergencies by hospitals has risen sharply in recent years.

**Methods**
For the purposes of the study, all 6,039 BARMER GEK insured persons who were admitted to a hospital between 1 September 2014 and 31 August 2015 with intervertebral disc damage in the lumbar region, and for whom a disc excision was performed for the first time, were interviewed. The response rate was 47 percent. The analysis was performed using descriptive statistics, bivariate analyses and logistic regressions.

**Findings**
Before undergoing a disc surgery, many people have a long history of suffering. For the employed, there is an added concern of being unable to practice their profession without the operation. Generally, there is a strong belief that the operation is the right way to remedy the back pain. The operation was urgent for more than three-quarters of the respondents.

For one-third of the respondents, conservative therapies were not consistently pursued, or operations were performed despite responses to these therapies. Looking only at the group in which emergency surgery can to the greatest degree possible be excluded, this proportion is still 29 percent. These people received operations even though the guidelines of the German Society of Neurosurgery state that conservative therapeutic approaches should initially be pursued. For persons who had a prior hospital consultation or obtained a second opinion, the share of operations conforming to the guidelines was significantly higher. Operations that did not conform to the guidelines were particularly pronounced among men and middle-aged patients.

More than 90 percent of respondents would elect to undergo the disc surgery again. More than half were completely or very satisfied with the success of the treatment. A total of 44 percent reported at least one complication. Nearly 10 percent of respondents suffered from serious complications for at least three months after the procedure.

The survey also revealed that there is a considerable gap between hospitals’ coding of cases as emergencies and the emergency criteria specified by the survey. Hospitals code cases as emergencies more
often than is justified by medical emergency indicators. Even in clearly normal cases, 5 percent of patients are coded as emergencies. On the other hand, a significant share of medical emergencies are not coded as emergencies.

**Conclusions**
The share of operations not performed according to guidelines is alarmingly high. Strengthening physician consultations and second opinions could induce more people to pursue conservative therapy approaches. Moreover, for employed patients, conservative therapies could be made more widely available, and their chances of success better explained. Particularly for people who perform hard physical labor or work changing shifts, and thus find it difficult to participate in conventional physiotherapy after work, specialized offers are advisable.

**Published in**
Orthodontic treatment from the perspective of young patients and their parents

Alexander Spassov, Bernard Braun, Hartmut Bettin, Sandra Meyer-Moock

Keywords: dentistry, orthodontics, braces, adolescents, children

Summary
Orthodontic treatment for children and adolescents up to 18 years of age has been part of the statutory-health-insurance benefit package for decades. Objective criteria play a critical role in the functioning of this regulation. However, there is no reliable information on orthodontic care from the subjective patient perspective.

To remedy this deficiency, two groups of children and adolescents were surveyed, along with their parents. The first group interviewed included children between 10 and 14 years of age who had recently begun a treatment (n=2,991, response rate 29%); the second included adolescents between the ages of 15 and 17 who had already completed a treatment (n=3,015, response rate 25%). Descriptive and multivariate methods were used for the statistical analysis.

Dentists’ recommendations (81%) were the primary driver for initiation of orthodontic treatment. A total of 7 percent of the child group and 25 percent of the adolescents group said they had experienced one or often more of the 16 functional (such as chewing problems) and 13 appearance-related (such as being teased) complaints before the beginning of treatment. About 60 percent of the adolescents who had completed treatment with a fixed appliance had previously received a removable retainer. Most of the adolescent patients reported themselves as being generally very satisfied (89%); on a more detailed level, the degree of satisfaction declined with the type and number of undesired events (i.e., long duration of treatment). A total of 61 percent were made not aware of the possibility of non-treatment. About 85 percent of parents said they had paid for additional services beyond the treatment financed by statutory health insurance. The average cost of these additional services amounted to € 1,200.

The survey shows that patient preferences are only partially taken account of in the course of orthodontic care. The self-determination rights of adolescents who undergo orthodontic treatment, as well as those of their parents, appear to be severely limited. The social regula-
tions governing orthodontic care should find a way to integrate patient preferences as leading quality criteria in the shared orthodontic-treatment decision-making process of patients, parents and dentists within the statutory health insurance system. Moreover, the regulatory system should provide better monitoring and more respect accorded to the profession’s ethical duties.

**Background**

The entitlement to orthodontic care in the statutory health insurance system, as well as its implementation and the evaluation of its quality, is primarily oriented toward objective criteria. Patient perceptions regarding the necessity for, the implementation of and the quality of such treatment are rarely considered, and are consequently not collected at any point. For this reason, the survey presented here addresses the following questions:

- How do children, young people and their parents perceive the decision-making process involved in orthodontic care?
- Are different treatment options addressed or explained? What level of quality is achieved by information and explanations about treatment options?
- How do the children and adolescents, as well as their parents, assess the quality of the process and particularly the quality of the outcomes of orthodontic treatment?
- What additional services are offered, to what extent, and for what reasons?

**Methods**

Individuals insured by BARMER GEK between the ages of 10 and 14 years (n=2,991, child or in-treatment group), as well as between the ages of 15 and 17 years (n=3,015, adolescents or already-treated group), as well as their parents, were surveyed using validated and standardized questionnaires. The first group included children that had begun orthodontic treatment within the last three to six months before the survey. The response rate in this group was 29 percent. The second group included adolescents who had completed orthodontic treatment with fixed appliances within the year prior to the survey. The response rate here was 25 percent.
Findings
Dentists’ recommendations are the primary driver for initiation of treatment with braces. Before the beginning of treatment, children’s functional and psychosocial problems played almost no role in terms of inducing treatment. The majority of patients received a removable appliance before the fixed appliance, and thus underwent treatment of a duration significantly longer than the international average. The overall degree of satisfaction with the treatment among children and their parents was high, but some open dissatisfaction was found with regard to specifics (i.e., duration of treatment). Approximately 61 percent of children say they were not advised of the possibility of non-treatment. About 85 percent of patients’ parents payed an average of € 1,200 for additional services related to the orthodontic treatment. Some of these services are not supported by scientific evidence.

Conclusions
The decision to engage in treatment is primarily made by the dental service provider. A large share of treatment events are not medically justified either subjectively through the child’s perception or objectively by the threat of health consequences deriving from non-treatment. Thus, there might be both excessive and unnecessary orthodontic care provided. From the patients’ perspective, criteria such as burden and duration of treatment, individualized information on treatment alternatives and their risks, treatment processes, and the likely additional financial expenditure associated with services financed by statutory health insurance are deemed to be important factors in the quality of treatment. Daily orthodontic practice seems to seldom involve criteria relevant to the patients, or a concrete and scientifically grounded representation of the advantages and disadvantages of treatment options and any additional privately financed services. Thus, what is needed are strategies for the implementation of scientifically based and patient-relevant criteria in orthodontic treatment within the statutory health insurance system, as well as for the strengthening of patients’ rights of self-determination.

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Colonoscopy for colorectal cancer screening – Patient experience and information needs
Maren Dreier, Kathrin Krüger, Ulla Walter

Keywords: colonoscopy, colorectal cancer, cancer screening, informed decision making

Summary
Since 2002, insured persons aged 55 years and older have been entitled to have two colonoscopies, 10 years apart, as an alternative to stool tests for colorectal cancer screening. In the future, an organized colorectal cancer screening program including an individual invitation will be implemented. Information on benefits and risks should be explicitly mentioned in the invitation letter to support an informed decision for or against screening.

Background and research question
A screening colonoscopy is a complex examination process with a higher potential for side-effects compared to other screening examinations. The goals of this paper are to summarize the insured persons’ experiences to date with the screening colonoscopy process, and to describe their informational needs. The following questions will be answered:
– How do insured persons perceive the process of preparation, the colonoscopy itself, and the post-examination phase?
– What barriers exist from the perspective of the insured persons?
– What information do insured persons consider important and relevant for decision making?

Methods
In November 2015, 5,975 BARMER GEK-insured persons aged 50 to 65 years were asked to complete a written survey. The data collected were merged with the routine dataset of the persons included using a key variable. The evaluation is based on frequency distributions, cross-tabulations, and multivariable logistic regression analyses.

Findings
The study population includes 1,871 insured persons (response rate 31%), with an average age of 58. The most common reason for under-
going a screening colonoscopy is the recommendation of a general practitioner (men: 69%; women: 51%). Appointments for the procedure are generally granted relatively quickly, at facilities close to the patients’ residences. Only a small minority reports severe discomfort; this is primarily experienced during the preparation process, and by women to a greater degree than by men. More than 90 percent of respondents report little or no pain during the examination. After the procedure, up to 25 percent experience moderate to strong discomfort due to flatulence. Overall, the examination is assessed by more than a third of the insured persons as not unpleasant. This is reflected by the fact that 94 percent of the respondents would undergo a further colonoscopy. Among the insured persons aged 50 to 54 years who are entitled to a future screening colonoscopy, 60 percent plan to do so. Here, a lower readiness to participate is associated with a higher level of education. Barriers include emotional reservations, particularly among women, as well as a lack of knowledge.

When asked what specific information is of personal importance to them, respondents give the top priority to details regarding risks and potential complications. Women more often attribute a high importance to individual informational aspects than men; this is particularly true for details regarding the possibility of pain during the examination. Insured persons with comparatively high education levels more often rate the individual information items as less important. Statements regarding the frequency of the malignant progress of benign polyps and the rationale behind their removal, as well as on the benefits and risks of the colonoscopy, seem to be particularly decision-relevant. Insured persons with lower education levels more often rate information on the pathogenesis of colorectal cancer, and practical aspects such as being unable to work on the day of examination, as decision-relevant.

**Conclusions**
Screening colonoscopies are in general accorded a high level of acceptance by the insured population. However, members of this population do not face the procedure wholly uncritically, but demand information on possible risks and complications. Accordingly, information rated as decision-relevant should be considered in future information and decision aids on colorectal cancer screening.
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Palliative care and assisted suicide
Saskia Jünger, Nils Schneider, Birgitt Wiese, Jochen Vollmann, Jan Schildmann

Keywords: hospice, palliative care, assisted dying, physician-assisted suicide, ending life upon request, palliative medicine, Act to Improve Hospice and Palliative Care

Summary
The starting point of this survey is the public and health-policy debate in the wake of legislation enacted in 2015 for the improvement of hospice and palliative care as well as on the prohibition of assisted suicide. Drawing on a large representative-population sample, the survey provides data on perceptions and evaluations of palliative care and assisted dying, and addresses in particular issues related to (physician)-assisted suicide, which remains the subject of societal and professional controversy following the recent passage of the law.

Background and inquiry
Palliative care has become increasingly widespread in Germany in recent years. Its further expansion has been bolstered by a broad societal consensus, while the 5 November 2015 passage of the Act for the Improvement of Hospice and Palliative Care anchors it deeply within the country’s health policy.

By contrast, suicide – particularly (physician) assisted suicide – is the subject of controversy within the palliative-care community as well as in the political, academic and public spheres. On 6 November 2015, a criminal prohibition against the “geschäftsmäßige” – that is, inclined to repetition – assisted suicide was passed. The debate on this issue has not been closed with the passage of the law, and is characterized by a number of different assumptions. On the one hand, it is feared that a legal provision that expressly allowed physician-assisted suicide under certain conditions could weaken society’s respect for life. In this case, palliative care expanded to universal availability is posed as an alternative to a regulation enabling physician-assisted suicide. On the other hand, supporters of assisted suicide as one legal option argue that even with good palliative care and symptom control, there will be people who want to end their lives. In addition, they say, a legal regulation could support compliance with quality standards,
such as the inclusion of palliative medicine experts in the decision-making process.

One characteristic of this controversy-laden discussion is the reference to preferences, experiences and assessments within the population. Against this background, empirical data on perspectives regarding the final phase of life are of great interest. This survey thus seeks to illuminate the following set of issues on practices at the end of life:

– What ideas do people have about dying under dignified conditions?
– What experiences have people had with the death of a person close to them due to serious, incurable disease?
– Do people have experience with palliative care?
– Can people imagine a situation in which someone would no longer wish to continue living despite good palliative care?
– In the respondents’ view, what (potentially) life-shortening interventions are part of the physician’s tasks in providing care at the end of someone’s life?
– For what groups of patients should physician-assisted suicide or ending life upon request be legally possible (and what groups should be excluded)?
– In the case of “unbearable suffering,” what proportion of people would desire physician-assisted suicide, ending life upon request or continuous sedation until death?

Methods
The survey of 1,598 citizens was conducted as part of the 23rd survey edition of the Gesundheitsmonitor 2015, using a standardized set of 12 questions. The data analysis was performed using descriptive statistics and bivariate analyses (χ² tests).

Findings
The desire to be free from pain and physical suffering is for most respondents the most important aspect for death under dignified conditions. While the predominant preferences concerning death with dignity can be addressed with high-quality palliative care, for many respondents, a desire to hasten death is conceivable even under conditions of good palliative care. Overall, a majority of citizens are inclined to consent to allowing assisted suicide and ending life on request.

Survey responses regarding the possible effects of a legal regulation enabling physicians to assist with suicide show a nuanced picture.
High levels of agreement were found for the expectations that unnecessary suffering would be reduced, the individual right to self-determination strengthened and respect for patients’ wishes improved. At the same time, a proportion of the respondents feared negative consequences, such as the risk of abuse and growing social pressure to opt for a “premature” death. A key finding of the survey is that a majority of respondents agree that doctors should first consult a palliative-medicine specialist in order to discuss therapeutic options for the relief of suffering.

The analyses of this general-population survey also show that when faced with questions regarding the end of life, a large proportion of citizens state that they are not able to judge, or simply do not answer the questions. This highlights the complexity of the subject, and indicates how difficult it is here to take a position detached from a concrete situation.

Conclusions
In summary, the expansion of hospice and palliative care in Germany accords with surveyed citizens’ priorities regarding death with dignity. However, focusing on palliative care as the only option in addressing the desire to hasten death does not do justice to the population’s nuanced preferences and values. Broad-based provision of palliative care combined with legal and professional leeway for the few patients who want to end their life with their physician’s support, appears to best reflect the nuanced preferences and values of people in the last phase of life as expressed in the survey.

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Health anxieties and patients' subjective experience of the doctor-patient interaction

Thomas Brechtel, Martin Buitkamp, Christoph Klotter

Keywords: anxiety, health anxieties, fears, trust, doctor-patient relationship

Summary
The term “health anxieties” is typically understood as indicating that people are fearful about their health. By contrast, the focus is not on what people fear in the health-care sector itself – for instance, whether they are afraid of going to see the doctor. To be sure, the idea that the doctor-patient relationship is a key aspect of medical treatment and decision making is widely held. However, patients’ fears in their interactions with doctors is not a focus in this approach to the subjective horizon. To date, there has been insufficient study of the effects of patients’ fears on the doctor-patient relationship and the utilization of medical services. An excessive fear of disease can lead to unnecessarily frequent doctors’ visits. On the other hand, fears of the doctor can greatly reduce the use of medical services, and prevent timely medical intervention, in some cases with high costs.

Background and inquiry
In dealing with the subject of fear, three main dimensions are significant:

– a fear that might be called “learned fear,” which is grounded in the insured individual’s unpleasant experiences with the doctor, and which can have a negative effect on the doctor-patient relationship;
– a fear that might be called “fear of a specific disease,” and can fundamentally contribute to avoiding the doctor – thus, to behavior that postpones necessary doctor visits; and
– a fear that might be called “fear due to an improper lifestyle,” and which can generally be regarded as an opportunity for change if there is insight regarding a behavior shift or action necessary in this situation.

This article first seeks to describe the current state of affairs with regard to the insured population’s health fears generally and specifically with respect to the doctor-patient interaction, as well the frequency of
those fears. Second, it will describe the influence of sociodemographic
dee parameters (gender, age, social status) and additional factors on the
level of anxiety. Third, it will examine the consequences of health
fears for patients’ behavior, especially with regard to avoiding or possi-
ibly increasing the frequency of doctor visits.

One hypothesis of this paper is that fears among a portion of the
population lead to the avoidance of or a delay in the use of health-care
services. A further hypothesis assumes that anxious people either
avoid or delay early-detection screenings out of fear that they will be
diagnosed with of a threatening disease. With regard to age, it is as-
sumed that in general, young people are more likely to be compara-
tively less anxious and comparatively less affected by diseases. The
hypothesis to be tested here is that health fears occur more often at
greater ages.

Methods
To pose these questions, a representative population survey was car-
ried out in the context of the 2015 Gesundheitsmonitor, conducted by
the Bertelsmann Stiftung and BERMER GEK (with a representative
population sample of respondents aged 18 to 79, n=1,598). Various
methods were used for the article’s descriptive, bivariate and multi-
variate analyses, including cross-tabulations with significance proof-
ing, and multivariate analyses with logistic regression.

Findings
With regard to health care, 57 percent fear that certain health services
will not be approved by their health insurance (particularly pro-
nounced among female respondents and among the lower and middle
social classes). Moreover, more than half (53%) expressed fears that
their personal health care will be deficient in the future due to a lack
of financing or quality. Generally a higher share of women express
fears than do men. Fear is also more pronounced among members of
the lower class than in the other social strata. Young people are more
likely to express health fears than are the older age groups. Respond-
ents clearly evince a high level of trust in their primary-care physi-
cians, who are perceived by the majority of respondents to be friends.
Doctor visits and the use of health care services tend to be delayed or
avoided more often by the comparatively more “fearful” people.
Conclusions
The results make clear that the “learned fear” resulting from insured persons’ (repeated) unpleasant experiences with the doctor or with visits to medical offices plays a rather minor role in the German health care system. Not every person automatically responds to a (serious) disease with a feeling of fear. Fear of the consequences of an “improper lifestyle” leads to an offer of preventative measures in the health sector. Actors in the health care sector should here help make different population and risk groups aware of the consequences of health-endangering behavior. Hints and activities that are formulated non-moralistically and take care not to increase fear further, instead taking the gentler form of “nudging” toward alternative behaviors, appear particularly expedient.

Against the background of this analysis, the role that statutory-health-insurance providers can play in combating health fears or reducing insured persons’ existing fears should also be examined. Health-policy discussions focusing on issues of financing clearly engender fear among the insured population that certain services will no longer be supported. Representatives of health-insurance providers would in this regard be advised to call greater attention to concrete aspects of care and other health issues. In parallel, it appears necessary to conduct the discussion about affordability in a way that transparently and openly acknowledges which statutory-health-insurance services will in the future be an aspect of solidarity, and which will not.

The medical profession should be informed and made aware that various population groups are or may be fearful to different degrees. One focus should be on men that deny their fears, along with socially less well-off individuals from lower social strata, with whom the physician should work particularly hard to establish a relationship of trust. The group of fearful people whose anxieties prevent them from utilizing medical services to an appropriate degree are particularly relevant to health policy.

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