

Patient participation and shared decision making in Germany – history, agents and current transfer to practice

Martin Härter^{1,*}, Hardy Müller², Jörg Dirmaier¹, Norbert Donner-Banzhoff³, Christiane Bieber⁴, Wolfgang Eich⁴

¹University Medical Center Hamburg-Eppendorf, Department of Medical Psychology

²Techniker Krankenkasse (TK), Scientific Institute of TK for Benefit and Efficiency in Health Care, Hamburg

³University Hospital Marburg, Department of General Practice

⁴University Medical Center Heidelberg, Department of General Internal Medicine and Psychosomatics

Summary

The main focus of the present paper is to describe 1) the healthcare system specific influences on patient participation in medical decision making and 2) the current state of research and implementation of shared decision making (SDM) after ten years of substantial advances in health policy and research in this field.

What about policy regarding SDM?

The “Medical Patients Rights Act” is to standardise all the rights and responsibilities within the scope of medical treatment. This also comprises the right to informed decisions, comprehensive and comprehensible information for patients, and decisions based on the partnership of clinicians and patients.

What about tools – decision support for patients?

SDM training programmes for healthcare professionals have been developed and partly implemented. Several decision support interventions – primarily with support from health insurance funds – have been developed and evaluated.

What about professional interest and implementation?

Against the background of the German health policy’s endorsement of patient participation, the German government and other public institutions are currently funding different research programmes in which shared decision making is playing a substantial role. The development and implementation of decision support tools for patients and professionals as well as the implementation of trainings for healthcare professionals require stronger efforts.

What does the future look like?

With the support of health policy and with the utilisation of scientific evidence, the transfer of shared decision making into practice is considered to be meaningful in the German healthcare system. The translation into routine care will remain an important task for the future.

Key words: patient participation, shared decision making, health policy, patient orientation, Germany
(As supplied by publisher)

*Corresponding author. Prof. Dr. Martin Härter, University Medical Center Hamburg-Eppendorf, Department of Medical Psychology, Martinistraße 52, D-22391 Hamburg.
Tel.: +49 40-7410-52978; fax: +49 40-7410-58170.
E-Mail: m.haerter@uke.uni-hamburg.de (M. Härter).

Patientenbeteiligung und Partizipative Entscheidungsfindung in Deutschland: Historische Entwicklung, Träger und Praxistransfer

Zusammenfassung

Ziel dieses Beitrags ist einerseits die Beschreibung, wie das deutsche Gesundheitssystem spezifischen Einfluss auf die Patientenbeteiligung bei medizinischen Entscheidungen nimmt. Andererseits werden der gegenwärtige Stand der Forschung und die Implementierung der Partizipativen Entscheidungsfindung (PEF; *Shared Decision Making*) 10 Jahre nach substantziellen Fortschritten in der Gesundheitspolitik und Forschung in diesem Feld ausgewertet.

Wie steht es mit gesetzlichen Regelungen zur PEF?

Das geplante Gesetz über Patientenrechte soll die Rechte und Verantwortlichkeiten bezüglich medizinischer Behandlungsmaßnahmen regeln. Es umfasst sowohl das Recht auf informierte Entscheidungen sowie umfassende und verständliche Informationen für Patienten als auch medizinische Entscheidungen, die partnerschaftlich von Ärzten (und anderen Gesundheitsberufen) und Patienten getroffen werden.

Wie steht es mit PEF-Instrumenten – Entscheidungshilfen für Patienten?

Spezifische Trainingsprogramme zur Partizipativen Entscheidungsfindung für medizinische Fachkräfte wurden entwickelt und teilweise

implementiert. Medizinische Entscheidungshilfen wurden – hauptsächlich mit Unterstützung von Krankenkassen – entwickelt und evaluiert.

Wie steht es mit dem Interesse der Profession und der Implementierung?

Vor dem Hintergrund der Unterstützung der Patientenbeteiligung durch die deutsche Gesundheitspolitik fördern die Bundesregierung und andere öffentliche Träger Forschungsprogramme, in denen Patientenorientierung und PEF einen Schwerpunkt bilden. Es sind jedoch noch verstärkte Anstrengungen im Bereich der Entwicklung und Implementierung von Entscheidungshilfen für Patienten sowie der Implementierung von Trainingsprogrammen für Gesundheitsberufe notwendig.

Wie sieht die Zukunft aus?

Mit der Unterstützung der Gesundheitspolitik und gestärkt durch wissenschaftliche Belege zur Wirksamkeit wird die Übertragung der PEF in das deutsche Versorgungssystem als bedeutsam eingeschätzt. Translation in die Routineversorgung ist eine wichtige Aufgabe für die Zukunft.

Schlüsselwörter: Patientenbeteiligung, Partizipative Entscheidungsfindung, Gesundheitspolitik, Patientenorientierung
(Wie vom Gastherausgeber eingereicht)

Introduction

The German health care system is based on solidarity and self-government and is contribution-financed. The health insurance system is composed of a mixture of statutory and private health insurance programs covering almost the entire population. For all insured persons, the health care benefits of the compulsory insurance are fundamentally equal and defined by law. This applies to approximately 89% of the population. The remaining 11% are insured through private insurance, in which the health care benefits are determined by different rates according to the needs of the insured person. Unlike many other European countries, Germany does not provide its citizens with health care through a centralised state-run system, but via a complex network of public bodies at law and a large number of independent regional and local bodies.

The goal of this article is 1) to clarify the specific health care system influences upon which patient participation, patient information, and the implementation of shared decision making in Germany are based. 2) The current status of milestones concerning training

programs, research, development and implementation of SDM will be described.

Patient participation in political decisions concerning health care (macro level)

Federal Joint Committee and Commissioner for Patients

The *Federal Joint Committee* (Gemeinsamer Bundesausschuss, www.g-ba.de) was institutionalised as a legal entity under public law formed by the *National Association of Statutory Health Insurance Physicians* (KBV), the *German Hospital Society* (DKG) and the *health insurance funds* in 2004. The task of the board is to substantiate which outpatient or inpatient medical benefits are adequate, practicable and cost-effective, and therefore belong to health services. Within the committee, patients, as official members, have *advisory and proposal rights*. Advisory rights include the sharing of experiences and of interests of patients and the self-help of chronically ill and

disabled persons. The proposal rights refer, for instance, to the acceptability of new research and treatment methods. Around 100 experts are involved as permanent patient representatives, who represent and counsel the Federal Joint Committee. Furthermore, in 2004, the Federal Government appointed the “*Commissioner for Patients of the Federal Government*” (rank of a state secretary) to represent patient interests. His foremost contribution is to strengthen patient rights and to advance these within the health care system (www.patientenbeauftragte.de).

Patient laws and juristic perspectives on shared decision making

In 1999, the *Conference of German Health Ministers* adopted the document “*Patient rights in Germany today*”. It is explicitly laid down that patients have the right to clear, expert and satisfactory education and counselling in order to explain the usage and risks of diagnostics, and advantages and risks of the treatment or non-treatment options. Physicians must be sure that patients have understood the information.

It is pre-assigned that patients must be informed about the type and possibility of different risks and their relation to recovery chances.

Further legal regulations that influence the diffusion of shared decision making are the *German Social Code* (SGB V, Paragraph 1 and SGB IX, Paragraph 9), which concerns patients' solidarity, responsibility and active participation in acute care as well as rehabilitation (including a "personal budget" for treatment decisions). In addition, the health insurance funds are assigned to support these goals through education and counselling. This law allows health insurance funds to implement contributions to the collective of the insured inhabitants in order to diffuse information for patients or develop decision aids. At the end of 2010, the *Commissioner for Patients of the Federal Government* announced a "Law on Patients' Rights" to come into force in 2011/2012. This law is to standardize all rights and responsibilities within the framework of medical treatment. This also comprises the right to informed decisions, comprehensive and comprehensible information for patients, and decisions based on the partnership of the clinician and patient.¹

National institutions supporting patients' medical decisions (meso level)

Institute for Quality and Efficiency in Health Care (IQWiG)

The *Institute for Quality and Efficiency in Health Care* (www.iqwig.de) is an independent, non-governmental and non-profit foundation that is intended to establish evidence-based reports on drugs, non-drug interventions, methods for diagnosis and screening, treatment guidelines and disease management programs. In addition, as an independent publisher of

¹(Submission for a modern law on patients' rights ("Für ein modernes Patientenrechtegesetz", Bundestag-Drucksache 17/907, <http://dip21.bundestag.de/dip21/btd/17/009/1700907.pdf>)

evidence-based consumer health and patient information, IQWiG has been providing *evidence-based health information* for patients and the general community since 2004. This information supports evidence-based decision making in the German health care services. Informed Health Online went online in 2006, and has covered more than 150 important medical topics so far (www.informedhealthonline.de).

Health insurance, self-help organizations and independent counselling services

It is in the responsibility of social health insurance funds to preserve or cure the health of their members or improve their medical condition (Social Security Code, Art. 1). Scientifically sound and efficient measures have to be applied (Art. 70). Patients' information and shared decision making are programmatically embedded. Within the framework of the Social Legislation Code (§ 65b, Volume Five), it is stated that independent organizations for patient counselling are funded by contributions from the mandatory health insurance. These organizations pursue the goal of securing independent, neutral and high-quality counselling for patients in Germany, in order to strengthen their autonomy and individual responsibility. These counselling facilities inform patients of their rights as patients, enable access to quality-assured patient information, and prepare the patient for the medical consultation (www.unabhaengige-patientenberatung.de).

This service has been legally established since the beginning of 2011 following a lengthy pilot phase.

The Social Legislation Code (§ 20c, Volume Five) also determines that self-help groups, organizations and contact offices are to be aided by the mandatory health insurance. Self-help groups should receive a contribution from the health insurance funds of €0.57 per year (2011) and per insured person. With this assistance, basic support for the existing organizations can be carried out, as well as the support of individually selected self-help projects. Self-help or-

ganizations are actively supporting the concept of shared decision making in Germany.

Agency for Quality in Medicine

Another non-governmental medical organization that strengthens patient influence on medical decisions is the *Agency for Quality in Medicine* (www.aeqz.de), which is a non-profit organization owned by the *German Medical Association* (BÄK) and the *National Association of Statutory Health Insurance Physicians* (KBV). The Agency has created a website, where information on health is reviewed by patients and experts regarding its quality and autonomy (www.patienten-information.de), and which links to reliable information sources for consumers and patients. Since medical treatment guidelines are difficult to understand for most patients, patient guidelines and decision support tools (mostly print materials) have been developed for the current *National Clinical Practice Guidelines* (indications: *asthma, chronic obstructive pulmonary disease, coronary heart disease, diabetes, depression*) and guidelines in oncology (*breast, prostate, and pancreatic cancer*)² in order to make the medical guidelines comprehensible and offer extensive information and support. Shared decision making, as the most valid clinician-patient approach for guideline-oriented recommendations, has recently been established as a therapeutic strategy (recommendation level B) for the first time within the National Clinical Practice Guideline on "Depression" [1]

German Network for Evidence-Based Medicine

Founded in 2000, the *German Network for Evidence-Based Medicine* (www.ebm-netzwerk.de/english) is a scientific association that, within one of its departments ("patient information and involvement"), expressly accepts

²Guideline program and decision tools supported by the German Cancer Association (DKG), the German Cancer Aid (DKH) and the Scientific Medical Societies in Germany (AWMF)

shared decision making. The area of information for patients and patient participation within this network consists of an aggregation of health professionals, health care researchers and representatives of the patient organizations and self-help groups. The functions of this department lie especially in the domain of educating people about the meaning and issues of evidence-based medicine, as well as in developing and dispersing evidence-based treatment information for laypersons, recently guidelines for health information (=Good Clinical Practice for Health Information, 2009)³.

Patient Universities

The first university for patients in Germany was founded in *Hannover* in October 2006 (www.patientenuniversitaet.de), and the second in *Jena* in October 2009. The universities' goals are to offer health education, empowerment, knowledge about healthcare structures and methodological principles to citizens and patients. The universities aim to address both experts and the general population. Specific educational provisions, which are oriented toward citizens, patients and their representatives, are designed to impart knowledge about responsibilities when treating illnesses, as well as knowledge of the structures of the health care system and methodological background for the assessment of study outcomes.

Health Targets and National Cancer Plan

Health targets.de (www.gesundheit.sziele.de) is a co-operation between the *Federal Ministry of Health (BMG)* and the *Association for Social Security Policy and Research (GVG)* and is funded by the Ministry. *Health targets.de* aims to strengthen the idea of target setting at all levels of the health care system and has so far been developing six specific health targets, one explicitly concerning the improvement of patients' and citi-

zens' competence in health-related issues. In 2008, the *National Cancer Plan* was started in Germany. This program, under the direction the *Federal Ministry for Health*, describes the main tasks to optimize oncologic care in four areas of action. In the area "Strengthening Patient Orientation", the aim of shared decision making has explicitly been described as follows:

- Patients have to be actively involved in making decisions regarding their care
- Evidence-based information should be provided to patients during therapy and care to support them in making decisions
- Shared decision making should be implemented⁴.

Patient participation in medical decision making (micro level)

The approach of patient participation in medical decision making has been discussed openly in Germany since the late 1990 s. However, the first publications in German [2–4] only discussed the approach conceptually. Clinical trials for the evaluation of patient participation in medical decision making were primarily initiated through the research program of the Federal Ministry of Health (www.shared-decision-making.org) [5]. Medical education at the universities concerning the topics physician-patient communication and decision making is executed at Institutes of Medical Psychology, Medical Sociology, Psychosomatics, and General Practice. In an older survey, 12 out of 23 Medical Psychology institutes (52%) disclosed that they have incorporated shared decision making into medical education [6], and that training efforts had been undertaken to prepare academic teachers for these courses. The current dissemination of SDM in medical education, and the implementation and importance of SDM, was again assessed in February 2011

via telephone interviews. Results can be reported from 24 of 32 Medical Psychology departments (Germany has 32 medical schools). 67% (N = 16) of those interviewed stated that SDM is part of their curriculum. On average, institutes spend 3-4 hours per semester on teaching SDM (lectures / seminars). The relevance of SDM within the curriculum has been rated with a mean of 5.3 (in 2006: mean 4.4, range: 0 to 10). Nine of the institutes indicated that they use SDM-specific teaching materials, of which five refer to a particular SDM training manual [30]. Thus, this update shows a moderate increase in the dissemination and importance of SDM in medical education in Germany compared to 2007.

Current state of national research on shared decision making

Since the funding of the research program "Patient as partner in medical decision making" (2001-2005), funded by the *German Ministry of Health (GMH)*, research in this subject has become measurably consistent. In a theory-guided consensus process, the German-language definition of patient participation in medical decision making (*Shared Decision Making = Partizipative Entscheidungsfindung - PEF*) was established [3]. Prior to the funding, individual work groups at different universities had researched this subject (www.evidence.de; www.gesundheit.uni-hamburg.de). Controlled studies have been made possible in large part by this research program [5].

Studies were implemented within five areas of internal medicine (hypertension [7], respiratory illnesses, arterial obstructive disease, breast cancer [8–10] and palliative care [11,12]) as well as five areas in the fields of neurology and psychiatry (multiple sclerosis [13–16], chronic pain [17–19], alcohol abuse [20], depression [21–24] and schizophrenia [25–27]). Furthermore, many questionnaires for the measurement of processes and outcome of shared decision making were

³ www.ebm-netzwerk.de/grundlagen/images/gpgj_2009_11.pdf

⁴ National Cancer Plan, Background Paper: <http://www.bmg.bund.de/glossarbegriffe/nationaler-krebsplan.html>.

Table 1. Patient participation and SDM in Germany.

Organizations advocating patient participation and SDM in Germany	
Federal Joint Committee Commissioner for Patients Institute for Quality and Efficiency in Health Care (IQWiG)	www.g-ba.de http://www.patientenbeauftragte.de www.iqwig.de www.informedhealthonline.de
Independent Patient Counselling Germany (UPD) Agency for Quality in Medicine	www.unabhaengige-patientenberatung.de www.aezq.de www.patienteninformation.de www.versorgungsleitlinien.de www.ebm-netzwerk.de
German Network for Evidence-Based Medicine Health Targets.de Patient Universities	www.gesundheitsziele.de www.patienten-universitaet.de www.gesundheitsuni-jena.de www.evidence.de
University Witten/Herdecke	
Research promotion / funding programs for SDM	
Federal Ministry of Health	http://www.bmg.bund.de "The patient as a partner in medical decision making" (www.shared-decision-making.org) "Chronic diseases and patient orientation" (www.forschung-patientenorientierung.de)
Federal Ministry of Health, Federal Ministry of Labour and Social Affairs, Health Insurance Companies and German Statutory Pension Insurance Scheme	
German Cancer Aid	"Research projects in psychosocial oncology care" (www.krebshilfe.de)
Tools for patients / physicians	
Universities of Marburg, Düsseldorf, Rostock	Decision aid for <i>cardiovascular prevention</i> (www.arriba-hausarzt.de)
University of Freiburg and University Medical Center Göttingen	German adaption of healthtalkonline.org , personal stories of patient experiences (www.krankheitserfahrungen.de)
AOK – Health Insurance; University of Bremen; German Cancer Research Center	Decision aid for patients facing <i>PSA screening</i> (www.psa-entscheidungshilfe.de)
AOK – Health Insurance Barmer-GEK Health Insurance	Decision aid for patients with <i>breast cancer</i> (www.aok.de/assets/media/bundesweit/entscheidungshilfebrust.pdf) Decision aid for <i>early detection of breast cancer – mammography screening</i> http://www.gesundheit.uni-hamburg.de/upload/BarmerMammografie2010.pdf
TK – Health Insurance, University of Freiburg	Decision aid for patients with <i>depression or acute low back pain</i> (www.tk.de/tk/kompetent-als-patient/tk-patientendialog/tk-patientendialog-starten/33818)
AOK – Health Insurance and Ludwig Boltzmann Institute for Health Technology Assessment	Decision aid for <i>HPV vaccination against cervical cancer</i> http://www.aok.de/portale/bundesweit/hpv/
Federal Ministry of Health, Universities of Freiburg and Hamburg	Decision aids for <i>dementia</i> Treatment of Alzheimer's disease http://www.demenz-leitlinie.de/Entscheidungshilfe-Behandlung.pdf Medication for Alzheimer's disease – yes or no? http://www.demenz-leitlinie.de/Entscheidungshilfe-Medikamente.pdf Caring of demented patients http://www.demenz-leitlinie.de/Entscheidungshilfe-Pflege.pdf
University of Hamburg	Decision aid for <i>colon cancer screening</i> http://www.gesundheit.uni-hamburg.de/upload/Darmkrebsinternet.pdf

developed and/or validated for the German context [28,29] (see contribution of Scholl and colleagues in this volume). From 2005 to 2007 training programs, transfer measures that partially use the train-the-trainer concept in further education, and promotion of concepts and

materials via internet and conferences were in the foreground [30,31]. A large national research fund consisting of grants from three Ministries (*Ministry of Health, Ministry of Education and Research, and Federal Ministry of Labour and Social Affairs*) and

of health insurance companies as well as the *German Statutory Pension Insurance Scheme (DRV Bund)* contracted out the amount of 21 million Euros for research projects within a six-year period (2008-2014); 42 projects are funded in the first period (-2011).

Studies are proposed within the three themes "Need-specific patient information" (1), "Patient education programs for chronically ill patients" (2) and "Organisation of participatory structure of health care" (3) (www.forschung-patientenorientierung.de). Ten projects are further investigating diverse SDM-related research questions and interventions (e.g. the development of shared goals in *coronary heart disease* or in *vocational rehabilitation*, the development of decision support interventions in *chronic diseases*, the transfer of "healthtalkonline.org" into German, the development and/or validation of *SDM-related assessment instruments*, or the evaluation of *interdisciplinary SDM training programs* for health professionals in rehabilitation clinics).

In addition, the *German Cancer Aid*, a non-profit organization with the goal of improving prevention, diagnosis, therapy, psychological care and self-help, is funding different research grants (two periods from 2008-2014, www.krebshilfe.de) for psychosocial oncology with an emphasis on patient orientation (background, development and implementation of the concepts of patient orientation and shared decision making in health care)⁵.

Other cooperation partners that support specific research and implementation projects are *health insurance funds*. Web-based patient decision aids and interactive health information systems, which include decision making aids for *prostate cancer screening*, *acute back pain*, and *depression* are being worked on and evaluated and realised via the websites of health insurance companies⁶. The *Scientific Institute of Techniker Krankenkasse for Benefit and Efficiency in Health Care* (WINEG) has defined patients' information as one issue of three fields of activity. In this field of activity, diverse areas of evidence-based patient information (EBPI) have been developed [32,33].

⁵ www.krebshilfe.de/fileadmin/Inhalte/Downloads/PDFs/Foerderung/2010_Psychosoz_Onkol_2/PSO_Ausschreibunstext_final_homepage.pdf

⁶ www.tk-online.de;
www.psa-entscheidungshilfe.de

Finally, decision support technologies have been developed and implemented in routine care through funding of the *Federal Ministry of Education and Research* (www.arriba-hausarzt.de). The electronic library of decision aids for general practitioners, "arriba-libTM", with "lib" being an acronym for "library", has a modular structure and currently contains evidence-based decision aids for the topics *cardiovascular prevention* [34–36], *atrial fibrillation*, *coronary heart disease*, *oral antidiabetics*, *conventional and intensified insulin therapy*, and *unipolar depression*. The modules are structured to assist physicians in counselling their patients according to the shared decision making philosophy. These steps can be regarded as a framework to help the clinician to effectively structure the encounter. The tools are, however, only available for general practitioners, organized within specific integrated care contracts at the moment.

Implementation strategies and perspectives of shared decision making in Germany

The dissemination of shared decision making is possible through different intervention strategies: Interventions for health care providers are mostly accomplished through publications, continuing education and training. The following table offers an overview of agencies, funding programs and tools advocating SDM in Germany (see Table 1).

Nationwide training interventions had been administered [30,31], and the implementation in communication programs in many of the German Medical schools has been rather successful [6]. However, the transfer to routine medical care still has a long way to go.

Despite promising individual research projects [14,15,34] as well as projects of different health insurance funds and the Agency for Quality in Medicine initiatives, the development of decision support materials and technologies in Germany is, in comparison to important

English-speaking countries, still lagging behind. This is an area in which the need for development and evaluation is very high. International and/or European efforts to adapt and transfer established decision tools may represent rational ways to proceed faster [37].

A clear indication for increasing implementation is the linking of shared decision making with the actions of secure quality management, self-help initiatives [38] and the patient safety initiative within the German health care. Patient participation in medical decision making is increasingly seen as a quality indicator for medical care and must therefore be addressed within the quality reports of hospitals and practices (patient orientation is already defined as a criterion within the certification process for quality management systems in hospitals and practices, see: www.ktq.de). Altogether, there are many different facets that have enabled the implementation of shared decision making in Germany. Shared decision making has been successfully initiated and paths for implementation evaluated. However, many steps still have to be taken to further develop and implement the approach of shared decision making in daily medical care.

Research was, and is, a strong driver in this field in Germany. At the end of 2010, the *Federal Government* passed the framework program "Health Research", in which the *Federal Ministry of Education and Research* is supporting research with more than five billion Euros between 2011 and 2014. It has explicitly been stated that one of the six action areas will focus on patient orientation, patient safety and processes for mutual decision making⁷.

Acknowledgement

We are grateful to Sarah Dwinger, Lisa Tlach, and Ivo Engert at the University Medical Center Hamburg-Eppendorf for their support in conducting the telephone survey (status of implementation

⁷ <http://www.bmbf.de/pub/gesundheitsforschung.pdf>

of shared decision making in medical schools' curricula). The authors thank Sarah Mannion (Berlin) for her translation and copyediting support.

References

- [1] Härter M, Klesse C, Bermejo I, Schneider F, Berger M. Unipolar depression: diagnostic and therapeutic recommendations from the current S3/National Clinical Practice Guideline. *Dtsch Arztebl Int* 2010;107(40):700–8.
- [2] Isfort J, Floer B, Koneczny N, Vollmar HC, Butzlaff M. Shared Decision-making: Arzt oder Patient: Wer entscheidet? *Dtsch med Wochenschr* 2002;127(39):2021–4.
- [3] Härter M. Partizipative Entscheidungsfindung (Shared Decision-Making) – ein von Patienten, Ärzten und der Gesundheitspolitik geforderter Ansatz setzt sich durch. *Z Arztl Fortbild Qualitätssich* 2004;98:89–92.
- [4] Dierks ML, Seidel G. Gleichberechtigte Beziehungsgestaltung zwischen Ärzten und Patienten – wollen Patienten wirklich Partner sein? In: Härter M, Loh A, Spies C, editors. *Gemeinsam entscheiden – erfolgreich behandeln. Neue Wege für Ärzte und Patienten im Gesundheitswesen*. Köln: Deutscher Ärzteverlag; 2005. p. 35–44.
- [5] Loh A, Simon D, Bieber C, Eich W, Härter M. Patient and citizen participation in German health care-current state and future perspectives. *Z Arztl Fortbild Qualitätssich* 2007;101(4):229–35.
- [6] Loh A, Simon D, Rockenbauch K, Härter M. Partizipative Entscheidungsfindung - Stellenwert und Verbreitung in der medizinischen Ausbildung. *Z Med Psychol* 2006;15(2):87–92.
- [7] Deinzer A, Veelken R, Kohlen R, Schmieder RE. Is a shared decision-making approach effective in improving hypertension management? *J Clin Hypertens* 2009;11(5):266–70.
- [8] Vodermaier A, Caspari C, Bauerfeind I, Kahlert S, Straub J, Untch M. Decision aids für Partizipative Entscheidungsfindung beim primären Mammakarzinom [Decision aids for shared decision-making in primary breast cancer]. *Z Arztl Fortbild Qualitätssich* 2004;98(2):127–34.
- [9] Vodermaier A, Caspari C, Koehm J, Kahlert S, Ditsch N, Untch M. Contextual factors in shared decision making: a randomised controlled trial in women with a strong suspicion of breast cancer. *Br J Cancer* 2009;24;100(4):590–7, 24.
- [10] Vodermaier A, Caspari C, Wang L, Koehm J, Ditsch N, Untch M. How and for whom are decision aids effective? Long-term psychological outcome of a randomized controlled trial in women with newly diagnosed breast cancer. *Health Psychol* 2011;30(1):12–9.
- [11] Schweitzer S, van Oorschot B, Köhler N, Leppert K, Steinbach K, Hausmann C, et al. Der Patient und seine Familie – Einstellungen und Mitsprachemöglichkeiten von Angehörigen palliativ behandelter Tumorpatienten. *Psychother Psych Med* 2005;55:298–304.
- [12] Van Oorschot B, Sayer B, Schaefer I. Palliativberatung im Modellvorhaben "Patienten als Partner – Tumorpatienten und ihr Mitwirken bei medizinischen Entscheidungen". *Z Palliativmed* 2005;6:90–4.
- [13] Kasper J, Köpke S, Mühlhauser I, Heesen C. Evidence-based patient information about treatment of multiple sclerosis-A phase one study on comprehension and emotional responses. *Patient Educ Couns* 2006;62:56–63.
- [14] Kasper J, Köpke S, Mühlhauser I, Nübling M, Heesen C. Informed shared decision making about immunotherapy for patients with multiple sclerosis (SDIMS): a randomized controlled trial. *Eur J Neurol* 2008;15(12):1345–52.
- [15] Köpke S, Kasper J, Mühlhauser I, Nübling M, Heesen C. Patient education program to enhance decision autonomy in multiple sclerosis relapse management: a randomized-controlled trial. *Mult Scler* 2009;15(1):96–104.
- [16] Heesen C, Kasper J, Segal J, Koepke S, Mühlhauser I. Decisional role preferences, knowledge and information interests in patients with multiple sclerosis. *Mult Scler* 2004;10:643–50.
- [17] Bieber C, Müller KG, Blumenstiel K, Schneider A, Richter A, Wilke S, et al. Long-term effects of a shared decision-making intervention on physician-patient interaction and outcome in fibromyalgia. A qualitative and quantitative one year follow-up of a randomized controlled trial. *Patient Educ Couns* 2006;63:357–66.
- [18] Hochlehnert A, Richter A, Bludau HB, Bieber C, Blumenstiel K, Mueller K, et al. A computer-based information-tool for chronic pain patients. Computerized information to support the process of shared decision-making. *Patient Educ Couns* 2006;61:92–8.
- [19] Bieber C, Müller KG, Blumenstiel K, Richter A, Hochlehnert A, Wilke S, et al. A shared decision making communication training programme for physicians treating fibromyalgia patients - effects of a randomized controlled trial. *J Psychosom Res* 2008;64(1):13–20.
- [20] Neumann T, Neuner B, Weiss-Gerlach E, Tonnesen H, Gentilello L, Wernecke KD, et al. The effect of computerized tailored brief advice on at-risk drinking in subcritically injured trauma patients. *J Trauma* 2006;61:805–14.
- [21] Loh A, Kremer N, Giersdorf N, Jahn H, Hänselmann S, Bermejo I, et al. Information and participation interests of patients with depression in clinical decision-making in primary care. *Z Arztl Fortbild Qualitätssich* 2004;98:101–7.
- [22] Loh A, Simon D, Hennig K, Hennig B, Härter M, Elwyn G. The assessment of depressive patients' involvement in decision-making in audio taped primary care consultations. *Pat Educ Couns* 2006;63:314–8.
- [23] Loh A, Leonhart R, Wills CE, Simon D, Härter M. The impact of patient participation on adherence and clinical outcome in primary care of depression. *Pat Educ Couns* 2007;65:69–78.
- [24] Loh A, Simon D, Wills CE, Kriston L, Niebling W, Härter M. The effects of a shared decision-making intervention in primary care of depression: a cluster-randomized controlled trial. *Pat Educ Couns* 2007;67(3):324–32.
- [25] Hamann J, Langer B, Winkler V, Busch R, Cohen R, Leucht S, et al. Shared decision-making for in-patients with schizophrenia. *Acta Psychiatr Scand* 2006;14:265–73.
- [26] Hamann J, Cohen C, Leucht S, Busch R, Kissling W. Shared decision-making and long-term outcome in schizophrenia treatment. *J Clin Psychiatry* 2007;68(7):992–7.
- [27] Reichhart T, Kissling W, Scheuring E, Hamann J. Patient participation in German psychiatry - a critical review. *Psychiatr Prax* 2008;35(3):111–21.
- [28] Simon D, Kriston L, Loh A, Spies C, Scheibler F, Wills C, et al. Confirmatory factor analysis and recommendations for improvement of the Autonomy-Preference-Index (API). *Health Expect* 2010;13(3):234–43.
- [29] Kriston L, Scholl I, Hölzel L, Simon D, Loh A, Härter M. The 9-item Shared Decision Making Questionnaire (SDM-Q-9). Development and psychometric properties in a primary care sample. *Patient Educ Couns* 2010;80(1):94–9.
- [30] Bieber C, Loh A, Ringel N, Eich W, Härter M. Patientenbeteiligung bei medizinischen Entscheidungen. Manual zur Partizipativen Entscheidungsfindung (Shared Decision Making). Publisher: Universitätsklinik Heidelberg und Freiburg; 2007.
- [31] Bieber C, Nicolai J, Ringel N, Blumenstiel K, Schneider A, Hartmann M, et al. Training physicians in Shared Decision-Making (SDM) - who can be reached and what is achieved? *Patient Educ Couns* 2009;77:48–54.
- [32] Genz J, Haastert B, Mayer G, Steckelberg A, Müller H, Cole D, et al. Blood glucose testing and primary prevention of diabetes mellitus type 2 – evaluation of the effect of evidence based patient information. *BMC Public Health* 2010;14(10):15.
- [33] Straub C, Niebling T, Müller H. Translating research into practice: A German sickness fund supporting patient participation. *Patient Educ Couns* 2008;73:544–50.
- [34] Krones T, Keller H, Sonnichsen A, Sadowski EM, Baum E, Wegscheider K, et al. Absolute cardiovascular disease risk and shared decision making in primary care: A randomized controlled trial. *Ann Fam Med* 2008;6(3):218–27.

- [35] Hirsch O, Keller H, Albohn-Kühne C, Krones T, Donner-Banzhoff N. Satisfaction of patients and primary care physicians with shared decision making. *Eval Health Prof* 2010;33(3):321–42.
- [36] Krones T, Keller H, Becker A, Sönnichsen A, Baum E, Donner-Banzhoff N. The theory of planned behaviour in a randomized trial of a decision aid on cardiovascular risk prevention. *Patient Educ Couns* 2010;78(2):169–76.
- [37] Albrecht K, Simon D, Buchholz A, Reuter K, Frosch D, Seebauer L, et al. How does a German audience appraise an American decision aid on early stage breast cancer? *Patient Educ Couns* 2010 Jun 3 [Epub ahead of print].
- [38] Simon D, Härter M. The principles of shared decision-making and the contribution of self-help institutions. *Bundesgesundheitsblatt Gesundheitsforschung Gesundheitschutz* 2009;52(1):86–91.