REVIEW ARTICLE

Decision Aids for Patients

Matthias Lenz, Susanne Buhse, Jürgen Kasper, Ramona Kupfer,
Tanja Richter, Ingrid Mühlhauser

SUMMARY

Background: Patients want to be more involved in medical decision-making. To this end, some decision aids are now available.

Methods: We present an overview of this subject, in which we explain the terms “shared decision-making”, “decision aid”, and “evidence-based patient information” and survey information on the available decision aids in German and other languages on the basis of a literature search in MEDLINE, EMBASE and PsycInfo and a current Cochrane Review. We also searched the Internet for providers of decision aids in Germany.

Results: Decision aids exist in the form of brochures, decision tables, videos, and computer programs; they address various topics in the prevention, diagnosis, and treatment of disease. They typically contain information on the advantages and disadvantages of the available options, as well as guidance for personal decision-making. They can be used alone or as a part of structured counseling or patient education. Minimal quality standards include an adequate evidence base, completeness, absence of bias, and intelligibility. Our search revealed 12 randomized controlled trials (RCTs) of decision aids in German and 106 RCTs of decision aids in other languages. These trials studied the outcome of the use of decision aids not just with respect to clinical developments, but also with respect to patient knowledge, adherence to treatment regimens, satisfaction, involvement in decision-making, autonomy preference, and decisional conflicts.

Conclusion: Only a small fraction of the available decision aids were systematically developed and have been subjected to systematic evaluation. Patients are still not receiving the help in decision-making to which medical ethics entitles them. Structures need to be put in place for the sustainable development, evaluation and implementation of high-quality decision aids.

► **Cite this as:**

Lenz M, Buhse S, Kasper J, Kupfer R, Richter T, Mühlhauser I: Decision aids for patients.
Dtsch Arztebl Int 2012; 109(22–23): 401–8.
DOI: 10.3238/arztebl.2012.0401

People have a right and an ethics-based entitlement to self-determination. They want to be involved in health- and disease-related decisions (1). This is especially relevant for measures that are aimed at healthy people (for example, screening tests for early detection of cancer), for measures with a dubious balance of benefit-to-harm, and for chronic diseases with an uncertain course, such as cancer or multiple sclerosis (MS).

Decisions that are made jointly by patients and physician are referred to as shared decision making (SDM) (2). Support for weighing the options in an individualized manner is given by decision aids (3) and evidence-based patient information (EBPI) (4).

This study aims to provide a descriptive overview of international and German decision aids as well as providers of decision aids in Germany. The concept of decision aid is discussed in the context of EBPI and SDM. Key aspects of the development, evaluation, and implementation are presented and exemplified using decision aid tools for MS.

An *eAppendix* with further information about quality criteria and decision aids (in German) is available on our homepage: www.chemie.uni-hamburg.de/igtw/Ge-sundheit/publikationen/pub_lenz.html

Shared decision making

There is no uniform definition of SDM (5). SDM represents a certain style of communication between patients and health professionals and takes place when the people involved in making the decision exchange relevant information in order to jointly make and implement a decision (6). According to the basic idea of evidence-based medicine (7), SDM should be based on reliable EBPI and take into consideration the participant's individual attitude.

Decision aids

Decision aids address preventive, diagnostic, and therapeutic measures and should help to balance individual options (3, 8). Their purpose is not to advise for specific measures or to increase treatment adherence. Decision aids are available as brochures, videos, web programs, or decision tables, and they incorporate various goals and teaching strategies (9). For example, supplying relevant information should motivate patients to reflect on their own attitudes and, consequently, to participate in decision-making. Conversely, motivating patients to think about their own values can represent an entry point into an

Hamburg University, School of Mathematics, Informatics and Natural Sciences, Unit of Health Sciences and Education: Dr. phil. Lenz, Buhse, Kupfer, Richter, Univ.-Prof. Dr. med. Mühlhauser

University Medical Center Hamburg-Eppendorf, Department of Primary Medical Care: Dr. phil. Kasper

BOX 1

Criteria for evidence-based patient information (4)

- **Criteria with good evidence for the cognitive endpoints knowledge, risk perception, comprehension, understanding:**
 - Numerical representation of numbers and results: absolute risk reduction, statistics in natural frequencies rather than in percentages, specified benchmarks
 - Linguistic representation of risks: no linguistic representation of risk (using words such as seldom, often, etc.) without giving additional numerical data
 - Graphical representation of data: pictographs, bar charts, and pie charts
- **Examples of relevant criteria, for which there is currently no good evidence regarding cognitive endpoints:**

As long as no evidence exists, target groups should provide feedback about how to implement these criteria:

 - Pictures and Drawings: illustrations of the text information
 - Narrative: patient reports and stories
 - Cultural characteristics: for patient information, the only approach to implementing this criterion is through oral communication
 - Layout issues: adjustment of font size, font type, contrast between background and font, and format, with respect to the target group
 - Language: easily understandable by the general public and specific for the target group; should promote participation

information process that encourages patients to participate in SDM.

Decision aid development is complex and usually includes a variety of theoretical and empirical groundwork (10). Since the use of decision aids can impact patient care (3), a thorough evaluation of their effectiveness through randomized controlled trials (RCTs) is required prior to their implementation.

Various tools are available to evaluate the quality of decision aids (8), including the International Patient Decision Aid Standards (IPDAS) Collaboration assessment checklist IPDASi (IPDAS instrument) (14), the instrument MATRIX to evaluate the development and evaluation processes of decision aids (9), and the instrument EQIP (Ensuring Quality Information for Patients) to evaluate information quality (15).

Evidence-based patient information

EBPI is a key component of decision aids, and internationally defined quality criteria are available (4, 11,

12). Ethical guidelines (13) clarify what content and meta-information for patients is relevant, and include

- information about the natural course of the disease (e.g., symptoms and prognosis of the disease without intervention);
- a comprehensive list of all options, which includes the possibility of (initially) refraining from intervention;
- the probability of success of, failure of, and harm from the upcoming medical interventions;
- patient-relevant outcomes;
- lack of evidence;
- data about possible false-positive and false-negative results for diagnostic measures.

EBPI should be easily understandable for the general public and presented in an unbiased manner. For some of the presented criteria, good evidence with respect to cognitive endpoints is lacking (*Box 1*). Developing health information requires that target group representatives are involved in the development process (4).

Developing EBPI is time-consuming and complex. Ensuring quality information requires, among other things, systematic searches for medical and scientific literature (for example, searching for the clinical picture of a disease, available options and their effectiveness) and a critical appraisal of these. Updating EBPI content is important, especially considering the current short half-life of scientific information.

Inventory

Methods

To identify non-German decision aids, database searches of the current Cochrane reviews (3) were supplemented with searches of MEDLINE (Ovid), EMBASE (Ovid) and PsycInfo (Ovid) up to August 2011 (*eAppendix*; available on our homepage [in German]). Decision aids were included if they met the Cochrane criteria and had been tested for effectiveness in RCTs.

To identify German decision aids, the term “patient information” was added to the search strategy and the language was limited to German (*eAppendix*). Known publications and reference lists of identified studies were searched for additional publications. Only those German decision aids were included in the study that met the Cochrane criteria and had been evaluated in RCTs.

A systematic database search was considered to be not appropriate for determining which providers are usually identified by lay people on the internet; instead, a Google search was done for the German terms “Entscheidungshilfe” (decision support) AND “Patient” (patient), and “evidenzbasiert” (evidence-based) AND “Patienteninformation” (patient information). The first 100 hits were screened for providers. Moreover, websites of known providers were screened for decision aids or EBPI as well as for links to other providers. Identified providers were assigned to one of three categories (*Table 1*).

TABLE 1

Providers of decision aids and patient information in Germany

Provider (example) ^{*1}	Offer (excerpt)
Provider of evidence-based patient information (EBPI)^{*2}	
Internet portal (Institute for Quality and Efficiency in Health Care, IQWiG) http://www.gesundheitsinformation.de	"Evidence-based health information" on various topics/areas (e.g., heart and circulatory system, immune system and infections, children and family, head and nerves, cancer, muscles, bones and joints, kidneys and urinary tract, and surgery and prevention). Indication-specific EBPI for the patient to fill out with information provided
German Federal Joint Committee http://www.g-ba.de/informationen	Patient information for chronic obstructive pulmonary disease (COPD) and asthma
German Medical Association and National Association of Statutory Health Insurance Physicians http://www.patienten-information.de	Succinct information for patients with selected diseases such as cancer, heart attack, stroke, or respiratory disease
Unit of Health Sciences and Education, Hamburg University www.patienteninformation.de	Health information on various topics (e.g., hormone treatment, colon cancer screening, mammography, cervical cancer screening, HPV vaccine and multiple sclerosis, prevention of osteoporosis, and pain management during surgery)
Providers of decision aids^{*3}	
Center for Psychosocial Medicine, University Medical Center Hamburg Eppendorf; "Patient as Partner" http://www.patient-als-partner.de	Decision aids on various topics (e.g., breast cancer, colon cancer, cervical cancer, cardiovascular disease, depression, dementia, and vaccinations)
Unit of Health Sciences and Education, Hamburg University http://www.chemie.uni-hamburg.de/igtw/Gesundheit	Evidence-based decision aids (prevention of heart attacks and multiple sclerosis)
Catholic Hospital Association Hellweg http://www.katharinen-hospital.de	Decision aid: "Feeding tube: yes or no?" for patients, relatives, and staff
AOK general health insurance company http://www.aok.de/bundesweit	Decision aids on various topics (e.g., PSA test, mastectomy or breast-conserving therapy, vaccinations, and artificial nutrition in old age), provided by the AOK-Bundesverband
Techniker Krankenkasse (TK) http://www.tk.de/tk/medizin-und-gesundheit	Portal "Competent as a patient" (e.g., courses and workshops, patient information, information evaluation, http://www.tk.de/tk/beratungsangebote/kompetent-als-patient/informationen-bewerten/225904); how to carry out successful physician consultations, use medication safely, and decision aids; decision aids (e.g., for breast cancer screening, early detection of colorectal cancer and cervical cancer, and HPV vaccine)
Provider of patient information, information brochure, etc. ^{*4}	
German Cancer information service (KID) http://www.krebsinformationsdienst.de	KID information sheets on various topics; brochures, images, audio files, and films about cancer
National Association of Statutory Health Insurance Physicians (KBV) http://www.kbv.de/patienteninformation	Information about various diseases (e.g., cancer, heart attack, stroke, and respiratory diseases)

^{*1} This table is not meant to be exhaustive but rather to reflect an internet search with the search engine Google; the terms "Entscheidungshilfe" (decision support) AND "Patient" (patient), and "evidenzbasiert" (evidence-based) AND "Patienteninformation" (patient information), were entered, and the first 100 hits were screened.

^{*2} Information was labeled by provider as "EBPI"

^{*3} Material was referred to by the provider as decision aid

^{*4} Evidence base is not reported by the providers, but "evidence-based" was claimed to be a feature, e.g. in the provider's quality standard

Results

International decision aids tested for efficacy

From the recent Cochrane review (3), 82 RCTs for non-German decision aids were initially extracted. From our own database research over the period January 2009 to August 2011, we identified and assessed 3693 titles and 54 publications (with full texts). Of these, we included 24 publications that covered 20 decision aids, and excluded 30 that did not contain a RCT or that evaluated a decision aid that did not meet the Cochrane criteria. In addition to the RCTs included in the current Cochrane review, we identified 106 RCTs for non-German decision aids (additional figures and tables are available [in German] on our homepage).

Decision aids address a variety of preventive, diagnostic and therapeutic options (3) and are to be used individually or as components of SDM programs. Additionally, consultations with physicians and health care professionals often take place. The main evaluation parameters considered knowledge, attitude, decisions taken, informed choice, decision confidence, patient satisfaction with respect to the decision, and patient preferences.

German decision aids tested for effectiveness

Of the 391 titles identified, we tested 339 and evaluated 19 based on their full texts. A total of 12 RCTs of 10 German decision aids were included (Table 2); seven of

BOX 2

Phases of development and implementation (10), as exemplified by the multiple sclerosis relapse therapy

- **Phases of development:**
 - theoretical framework (protection motivation theory, shared decision making, evidence-based patient information) (e18)
 - patient preferences and attitudes (e1)
 - systematic review of the literature (e2)
- **Planning and pilot phase**
 - development of a brochure and a training program with experts and multiple sclerosis patients (e8)
 - pre-testing of the components and the entire program (e8)
 - determination of primary and secondary results parameters (16)
 - development and pre-testing of survey tools (16)
- **Evaluation phase**
 - Multicenter RCT with 150 persons with relapsing-remitting multiple sclerosis (16)
- **Implementation phase**
 - creation of an updated decision support (e4)
 - development of a train-the-trainer program (e4)
 - evaluation of the program implementation with 261 persons with relapsing-remitting multiple sclerosis (e4)

the full-text publications were excluded because they did not contain RCTs or did not evaluate a decision aid. Four of the 12 RCTs that we included are also in the current Cochrane review.

In addition to indication-specific clinical endpoints, we also evaluated knowledge, treatment adherence, patient satisfaction, patient participation in decision-making, autonomy preferences, and decision conflict as parameters for results. RCT validity was not assessed here (additional figures and tables are available [in German] on our homepage).

Providers of decision aids in German

We identified several German providers of decision aids (Table 1), as well as providers of patient guidelines or patient information, who based their content on guidelines from scientific medical societies (for example, the German Society of General Practice and Family Medicine [Deutsche Gesellschaft für Allgemeinmedizin und Familienmedizin]). We even identified internet sites which did not directly provide in-

formation but rather gave links to providers, decision aids, and EBPI (for example, the German Network for Evidence-Based Medicine [Deutsches Netzwerk evidenzbasierte Medizin] and the German Cochrane Centre [Deutsches Cochrane Zentrum]). However, it was not possible for most providers to determine to which extent information is actually evidence-based.

Development, evaluation, and implementation, as exemplified for multiple sclerosis

Funded by the German Federal Ministry of Health (2001–2004), the Unit of Health Sciences and Education at the University of Hamburg, in collaboration with the University Medical Center Hamburg-Eppendorf (UKE), developed and evaluated two decision aids for people with multiple sclerosis (MS) (Box 2). The decision aid on immunotherapy is composed of a detailed information brochure and a decision worksheet. In addition to the detailed information brochure (e1), a second decision aid for MS relapse management is provided through a four hour group training, discussion and reflection for patients with MS and their relatives (16). Relapse management faces several uncertainties and is prototypical for the use of decision aids, since relapses can differ greatly and have unclear prognostic significance (e2). Guidelines recommend a short-term, high-dose intravenous therapy with glucocorticoids (e3), yet this is based on weak evidence: Only short-term effects have been demonstrated (with no apparent long-term benefit of administering oral glucocorticoids over placebos), and adverse effects are common and can be severe (e2).

Since no evidence-based decision aids were available (17), decision aids were developed based on several preliminary studies. The decision aids should help people with MS to recognize that, in the event of a relapse, they have several possible choices, including the option of waiting. People with MS were involved in all stages of development. Two people conducted the training: a nurse and one person with MS.

RCTs revealed that fewer relapses occurred following intervention with intravenous therapy (22% rate of relapses in the intervention group) as compared to the control group (44%, $p < 0.0001$), and that patients receiving the intervention had increased knowledge of risk and were more autonomous in their decision-making (16).

In the subsequent implementation study (e4), 31 participants were trained in a train-the-trainer program to provide the decision aids at various centers across Germany. The results of 261 participants with MS demonstrated that the program could be put into practice, but with different implementation barriers.

At present, the program is solidly implemented at two rehabilitation centers for people with MS, the UKE outpatient clinic and a self-help organization. The program was transferred to a Canadian center at the end of 2011 (additional figures and tables are available [in German] on our homepage.)

TABLE 2

German-language decision aids with proven effectiveness

No.	Topic	Decision aid and link ^{*1}	Study	Study participants (P), intervention (I), control intervention (C), outcome parameters (O)
1.	Breast cancer treatment	Three indication-specific EBPI brochures: – Breast-conserving therapy or mastectomy? – additional chemotherapy in hormone receptor-positive breast cancer (T1) (brochure only) – preoperative chemotherapy or postoperative chemotherapy in T2 or T3 www.aok.de/assets/media/bundesweit/entscheidungshilfebrust.pdf	Vodermaier 2009 (e9) Vodermaier 2011 (e10)	P: doctors, patients (n = 111) I: one of three indication-specific EBPI + decision board; C: standard treatment; O: decisional conflict, decision, duration of medical advice, time point of decision, patient participation in the decision-making process and in the decision, and patient satisfaction P: doctors, patients (n = 98) I: one of three indication-specific brochures + decision board; C: standard treatment; O: decisional conflict, fear + depression, body awareness, perceived control; coping
2.	Abdominal surgery: laparoscopic cholecystectomy	Interactive DVD cholecystectomy	Wilhelm 2008 (e11)	P: patients prior to deciding for or against cholecystectomy (n = 212) I: interactive DVD to support patient-training; C: conventional patient consultation by surgeon; O: knowledge of disease, natural course, surgical procedure and possible complications; satisfaction with training
3.	Colon cancer screening	Colon cancer: early detection www.gesundheit.uni-hamburg.de/upload/NeueDarmkrebsbroschuere2011.pdf	Steckelberg 2011 (25)	P: GEK insurees, 50 to 75 years old (n = 1577) I: EBPI brochure, two optional interactive internet learning modules; C: official brochure of the German colorectal cancer screening program of the Federal Joint Committee O: "informed choice" (knowledge, attitude, actual/planned use)
4.	Diabetes mellitus	Prediabetes—the unrecognized risk on the road to type 2 diabetes	Genz 2010 (e12)	P: visitors to the websites of TK and the German Diabetes Center who do not have a diagnosis of diabetes I: internet-based EBPI; C: standard information; O: knowledge, attitudes to metabolic control, intention to undertake metabolic control, decisional conflict (DCS), satisfaction with the information
5.	Depression	Decision aids for treating patients with depression www.depression-leitlinien.de/depression/media/Entscheidungshilfe_Deutsch.pdf	Loh 2007 (23)	P: doctors (cluster, n = 23), patients with newly-diagnosed depression (n = 287) I: medical training, EBPI brochure, decision board, advisory module; C: standard treatment; O: patient involvement, satisfaction, consultation duration, severity of depression, treatment adherence
6.	Heart attack and stroke: risk assessment and prevention	ARRIBA-Herz www.uni-marburg.de/fb20/allgprmed/arriba/arriba%20in%20sechs%20schritten	Krones 2008 (e13) Krones 2009 (e14) ²	P: primary care practices (cluster, n = 14), patients with indication for cardiovascular prevention (n = 1132) I: medical training, patient counseling strategy including decision aids and risk prediction tools; C: medical seminars on alternative topics; O: patient involvement, SDM (SDM-Q), decisional regret, knowledge (e13), TBT scale (e14) ²
7.	Multiple sclerosis: immunotherapy	Informed shared decision making in multiple sclerosis immunotherapy (ISDIMS) www.gesundheit.uni-hamburg.de/upload/Immuntherapien%20der%20MS.pdf	Kasper 2008 (e15)	P: patients with MS (n = 297) I: brochures, interactive worksheets; C: standard information material (DMSG); O: accordance between the role the patient desired and the one they experienced in decision making
8.	Multiple sclerosis: relapse therapy	Evidence-based self-management in multiple sclerosis (EBSIMS) www.gesundheit.uni-hamburg.de/upload/Schubtherapie_der_MultiplenSklerose.pdf	Köpke 2008 (16)	P: patients with MS (n = 150) I: EBPI brochure, education program; C: standard information materials; O: relapse therapy, number and severity of relapses, autonomy preference (CPS), quality of life (HAQUAMS), functional status (UNDS)
9.	Back pain: bodily function improvements through behavior change and exercise	Back pain www.arztbibliothek.de/mdb/downloads/kip/aezq-version-kip-akuter-kreuzschmerz.pdf	Bücker 2010 (e16)	P: patients in primary care practices with acute, uncomplicated back pain (n = 174) I: EBPI brochure C: leaflet about a non-back pain-related topic; O: physical function impairment by back pain, functional ability, attitude, and knowledge about back pain

No.	Topic	Decision aid and link ^{*1}	Study	Study participants (P), intervention (I), control intervention (C), outcome parameters (O)
10.	Schizophrenia: treatment options	Schizophrenia	Hamann et al. 2006 (e17)	P: 12 hospital wards for psychiatric acute patients, patients with schizophrenia (n = 107) I: decision aids and medical consultation (SDM); C: standard treatment; R: knowledge, the patient's wish to be involved in the decision making process (API), attitudes toward treatment options (DAI), patient involvement (COM-RADE), satisfaction (ZUF8); doctors and nurses completed additional patient-related questionnaires

^{*1} internet link, only if decision aids are available free online;

^{*2}Krones 2009 (e14) is a validation study for the TBT scale within the framework of a RCT (e13); API, autonomy preference index; COMRADE, combined outcome measure for risk communication and treatment decision making effectiveness; CPS, Degner Control Preference Scale; DAI, decision attitude index; DCS, Decisional Conflict Scale; DMSG, German Multiple Sclerosis Society; DVD, digital video disc; EBPI, evidence-based patient information; GEK, Gmünder Ersatzkasse; HAQUAMS, Hamburg Quality of Life Questionnaire in Multiple Sclerosis; MS, multiple sclerosis; SDM, shared decision making; SDM-Q, shared decision making questionnaire; TBT, theory of planned behavior; UNDS, UK Neurological Disability Scale; ZUF8, Zufriedenheit 8

Discussion

The authors identified several internet sites that offer a variety of information which is labeled as evidence-based patient information or decision aid. However, whether the content is indeed evidence-based is often difficult to determine.

Patients who search the internet for decision aids are likely to use terms for their individual indications, such as “diabetes” or “heart attack.” Although this review does not address indication-specific searching, the lack of clarity in our obtained search results is likely to be similar to that of indication-specific searches.

The copious amount and variety of available information contrasts starkly with the absence of high-quality decision aids. A yet unresolved problem is the non-transparency of information quality. Even when patient information and decision aids are labeled as “evidence-based,” the content and presentation of information is often not evidence-based (18). Different quality seals, such as “Health on the Net” (HON) (e5) or DISCERN (e6), should demonstrate that the information is reliable. In Germany, for example, the HON seal is used on patient information sites from the Institute for Quality and Efficiency in Health Care (Institut für Qualität und Wirtschaftlichkeit im Gesundheitswesen, IQWiG), the German Medical Association (Bundesärztekammer, BÄK), and the National Association of Statutory Health Insurance Physicians (Kassenärztliche Bundesvereinigung, KBV) (Table 1). However, central EBPI quality aspects such as scientific accuracy, completeness, and content presentation are not taken sufficiently into consideration by the quality seal (19). Users currently have little opportunity to assess the reliability of the information available.

Much of what is labeled as decision aid is freely available through the internet. However, our database searches revealed that relatively few decision aids have been evaluated for benefit and harm in RCTs. On the other hand, there are good examples of German-language decision aids that have been systematically developed and have been proven to be effective (Table 2).

It is difficult to draw a clear conceptual distinction between EBPI and decision aids. If an EBPI is designed to be used for decision-making, it basically satisfies the IPDAS-criteria (8). Additionally, EBPI can function alone, as exemplified by the “drug facts box” (e7), in which the benefits and adverse effects of a drug are directly compared using absolute risks. In fact, a RCT demonstrated that a drug facts box, as compared to standard information, improved knowledge about benefits and adverse effects of a drug and may help to correct unrealistic expectations about their effectiveness (e7).

Prior to implementing a decision aid, its effectiveness should be tested in a RCT. To evaluate how a decision aid works under certain conditions, it is usually necessary to conduct additional theoretical work and empirical preliminary studies. Systematical retrieval of all available trial publications is a methodological problem (20). One proposal for overcoming this is to develop specifically structured literature databases that allow complete identification, which would facilitate quality assessment (21, 22). An additional problem is obtaining a critical appraisal of identified literature. On the one hand, the published works are methodologically heterogeneous, which requires that the assessor has a broad methodological knowledge. On the other hand, the conditions (contextual factors) under which the decision aids were developed and/or evaluated are not always transparent. In these cases, whether a decision aid will be successful or counterproductive for users under the user's terms and conditions remains an open question.

Whether using a decision aid is helpful for a patient to reach a decision can depend on several factors. A basic requirement is that patients understand the contents, and this must be verified. In this context, health care professionals such as breast-care nurses or diabetes educators could play stronger roles (1). Additionally, successful implementation appears to require that doctors and medical staff are trained in evidence-based medicine and SDM, among other things (23, e6).

The work presented here is not a systematic review but rather an inventory of compiled literature, which was not systematically analyzed. A systematic review

was published by the Cochrane Collaboration (3). It was updated in October 2011 but only contains research until December 2009. In contrast to the Cochrane review, the present work reflects various aspects of the development, evaluation and implementation of decision aids, foremost in Germany.

Summary

People want to have access to complete, unbiased and comprehensive evidence-based information, and indeed they have a right and an ethics-based entitlement to this; however, this need is currently inadequately met. Structures have to be developed that allow high-quality decision aids and evidence-based patient information to be sustainably developed, evaluated and implemented. This is especially urgent for cancer and other chronic diseases.

Quality criteria for decision aids should be developed, catalogued, and validated. These criteria should go beyond IPDAS criteria and take into consideration whether contents are evidence-based as well as the transparency of the development, implementation and evaluation of the contents. Currently, guidelines are being developed for health information providers, which should improve the quality of information in the long term (24).

To make German indication-specific decision aids available, it will be necessary to create an independent and publically-available database where authors could provide current decision aids and meta-information. In addition to available evidence about development and evaluation, this database should include quality information about whether the contents are evidence-based and about the implementation conditions.

KEY MESSAGES

- People who are facing health or disease-related decisions have a right and an ethics-based entitlement to evidence-based patient information and for participation in these decisions.
- Decision aids should provide evidence-based information and support individual decision processes.
- Decision aids are interventions that have an impact on patient care and must be evaluated prior to their use; the minimum quality standards are that their contents are evidence-based, complete, unbiased, and comprehensible.
- Relatively few decision aids have been evaluated for their beneficial and detrimental effects in RCTs. Few decision aids have been assessed with respect to their effectiveness in reaching better decisions.
- A reliable quality assessment of decision aids is hardly possible for users, since information about the evidence base of the contents or the development, effectiveness, and implementation conditions for the aid are usually neither transparent nor easily identifiable.

Acknowledgment

We would like to thank Martina Bunge, Anja Gerlach, Sascha Köpke, and Anke Steckelberg for their highly constructive contribution to this work.

Conflict of interest statement

The authors declare that no conflict of interest exists.

Manuscript submitted on 24 October 2011, revised version accepted on 16 January 2012.

Translated from the original German by Veronica A. Raker, PhD.

REFERENCES

1. Mühlhauser I, Meyer G, Steckelberg A: Patienten wollen mitentscheiden, doch Informationsbasis und Strukturen fehlen. *ZFA* 2010; 86: 412–7.
2. Edwards A, Elwyn G: Shared decision making in health care: achieving evidence based patient choice, 2 e. Oxford: Oxford University Press 2009.
3. Stacey D, Bennett CL, Barry MJ, et al.: Decision aids for people facing health treatment or screening decisions. *Cochrane Database of Systematic Reviews* 2011; CD001431.
4. Bunge M, Mühlhauser I, Steckelberg A: What constitutes evidence-based patient information? Overview of discussed criteria. *Patient Educ Couns* 2010; 78: 316–28.
5. Charles C, Gafni A, Freeman E: Implementing shared decision making and treatment decision aids: A cautionary tale. *Psicooncologia* 2010; 7: 243–55.
6. Charles C, Gafni A, Whelan T: Shared decision-making in the medical encounter: what does it mean? (Or it takes at least two to tango). *SocSciMed* 1997; 44: 681–92.
7. Strauss S, Glaziov P, Richardson WS, Haynes RB: Evidence-based medicine: how to practice and teach it. 4th edition. Edinburgh: Churchill Livingstone 2010.
8. International Patient Decision Aid Standards (IPDAS) Collaboration: International Patient Decision Aid Standards. <http://ipdas.ohri.ca/>.
9. Lenz M, Kasper J: MATRIX – development and feasibility of a guide for quality assessment of patient decision aids. *GMS Psychosoc Med* 2007; 4: Doc10.
10. Craig P, Dieppe P, Macintyre S, Michie S, Nazareth I, Petticrew M: Developing and evaluating complex interventions: new guidance. UK Medical Research Council 2008. www.mrc.ac.uk/complexinterventionsguidance
11. Steckelberg A, Berger B, Köpke S, Heesen C, Mühlhauser I: Kriterien für evidenzbasierte Patienteninformationen. *Z Arztl Fortbild Qualitatssich* 2005; 99: 343–51.
12. Trevena LJ, Davey HM, Barratt A, Butow P, Caldwell P: A systematic review on communicating with patients about evidence. *Journal of Evaluation in Clinical Practice* 2006; 12: 13–23.
13. General Medical Council: Consent: patient and doctors making decisions together. www.gmc-uk.org/guidance/ethical_guidance/consent_guidance/Consent_guidance.pdf.
14. Elwyn G, O'Connor AM, Bennett C, et al.: Assessing the quality of decision support technologies using the International Patient Decision Aid Standards instrument (IPDAS). *PLoS ONE* 2009; 4: e4705.
15. Charvet-Berard AI, Chopard P, Perneger TV: Measuring quality of patient information documents with an expanded EQIP scale. *Patient Education & Counseling* 2008; 70: 407–11.
16. 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. *Multiple Sclerosis* 2009; 15: 96–104.
17. Köpke M, Mühlhauser I: Decision aids in multiple sclerosis. In: Edwards A, Elwyn G, (eds.): Shared decision making in health care: achieving evidence based patient choice, 2e. Oxford: Oxford University Press; 2009: 257–61.

18. Feldman-Stewart D, Brennenstuhl S, McIsaac K, et al.: A systematic review of information in decision aids. *Health Expect* 2007; 10: 46–61.
19. Köpke S, Berger B, Steckelberg A, Meyer G: In Deutschland gebräuchliche Bewertungsinstrumente für Patienteninformationen – eine kritische Analyse. *Z Arztl Fortbild Qualitätssich* 2005; 99: 353–7.
20. Lenz M, Kasper J, Mühlhauser I: Searching for diabetes decision aids and related background information. *DiabetMed* 2006; 23: 912–6.
21. Lenz M, Steckelberg A, Richter B, Mühlhauser I: Meta-analysis does not allow appraisal of complex interventions in diabetes and hypertension self-management: a methodological review. *Diabetologia* 2007; 50: 1375–83.
22. Warsi A, Wang PS, LaValley MP, Avorn J, Solomon DH: Self-management education programs in chronic disease: a systematic review and methodological critique of the literature. *ArchInternMed* 2004; 164: 1641–9.
23. Loh A, Simon D, Wills CE, Kriston L, Niebling W, Harter M: The effects of a shared decision-making intervention in primary care of depression: A cluster-randomized controlled trial. *Patient Education and Counseling* 2007; 67 (3 SPEC. ISS.): 324–32.
24. Steckelberg A: Projekt: Entwicklung und Pilotierung einer Leitlinie zur Erstellung und Präsentation von evidenzbasierter Patienteninformation (EBPI). www.chemie.uni-hamburg.de/igtw/Gesundheit/projekte/patientenleitlinie.html
25. Steckelberg A, Hülfenhaus C, Haastert B, Mühlhauser I: Effect of evidence based risk information on „informed choice“ in colorectal cancer screening: Randomised controlled trial. *BMJ* 2011; 342: d3193; doi:10.1136/bmj.d3193.

Corresponding author:

Dr. Matthias Lenz
 Universität Hamburg
 Fakultät für Mathematik, Informatik und Naturwissenschaften
 Gesundheitswissenschaften
 Martin-Luther-King-Platz 6
 20146 Hamburg, Germany
matthias.lenz@uni-hamburg.de

For eReferences please refer to:
www.aerzteblatt-international.de/ref2212

REVIEW ARTICLE

Decision Aids for Patients

Matthias Lenz, Susanne Buhse, Jürgen Kasper, Ramona Kupfer,
Tanja Richter, Ingrid Mühlhauser

eReferences

- e1. 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 Education & Counseling* 2006; 62: 56–63.
- e2. Köpke S, Heesen C, Kasper J, Mühlhauser I: Steroid treatment for relapses in multiple sclerosis – the evidence urges shared decision-making. *Acta Neurologica Scandinavica* 2004; 110: 1–5.
- e3. Deutsche Gesellschaft für Neurologie: Diagnostik und Therapie der Multiplen Sklerose. Leitlinien für Diagnostik und Therapie in der Neurologie; 4th revised edition 2008. www.awmf.org/uploads/tx_szleitlinien/030-050_S1_Multiple_Sklerose_Diagnostik_und_Therapie_10-2008_10-2013.pdf.
- e4. Köpke S, Richter T, Kasper J, Mühlhauser I, Flachenecker P, Heesen C: Implementation of a patient education program on multiple sclerosis relapse management. *Patient Education & Counseling* 2012; 86: 91–7.
- e5. Health On the Net Foundation (HON): www.hon.ch
- e6. DISCERN: www.discern.de
- e7. Schwartz LM, Woloshin S, Welch HG: Using a drug facts box to communicate drug benefits and harms: two randomized trials. *Annals of Internal Medicine* 2009; 150: 516–27.
- e8. Köpke S: Evidenz-basierte Patienteninformation und partizipative Entscheidungsfindung bei Multipler Sklerose. Dissertation, Universität Hamburg. http://ediss.sub.uni-hamburg.de/frontdoor.php?source_opus=3352.
- e9. 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. *British Journal of Cancer* 2009; 100: 590–7.
- e10. 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 Psychology* 2011; 30: 12–9.
- e11. Wilhelm D, Gillen S, Wirnhier H, Kranzfelder M, Schneider A, Schmidt A, et al.: Extended preoperative patient education using a multimedia DVD-impact on patients receiving a laparoscopic cholecystectomy: a randomised controlled trial. *Langenbecks Archives of Surgery* 2009; 394: 227–33.
- e12. Genz J, Haastert B, Meyer G, Steckelberg A, Müller H, Verheyen F, 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; 10: 15.
- e13. Krones T, Keller H, Sönnichsen A, Sadowski EM, Baum E, Wegscheider K, et al.: Absolute cardiovascular disease risk and shared decision making in primary care: a randomized controlled trial. *Annals of Family Medicine* 2008; 6: 218–27.
- e14. 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 Education and Counseling* 2009; 78: 169–76.
- e15. Kasper J, Köpke S, Mühlhauser I, Nübling M, Heesen C: Informed shared decision making about immunotherapy for patients with multiple sclerosis (ISDIMS): A randomized controlled trial. *European Journal of Neurology* 2008; 15: 1345–52.
- e16. Bückner B, Butzlaff M, Isfort J, Konecny N, Vollmar HC, Lange S, et al.: Effect of written patient information on knowledge and function of patients with acute uncomplicated back pain (PIK Study). *Gesundheitswesen* 2010; 72: e78–88.
- e17. 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; 114: 265–73.
- e18. Heesen C, Kasper J, Segal J, Köpke S, Mühlhauser I: Decisional role preferences, risk knowledge and information interests in patients with multiple sclerosis. *Multiple Sclerosis* 2004; 10: 643–50.