11. Kongress für Versorgungsforschung
4. Nationaler Präventionskongress
Plenary Session on Patient Orientation in Health Services Research

Patient Involvement in Medical Decision Making in Germany

Martin Härter
Universitätsklinikum Hamburg-Eppendorf
28.9.2012 - Dresden
Objectives

• The strong push for SDM in medicine
• (Inter)national research efforts in SDM
• Implementation and health services research
Changes in the clinician-patient-relationship

1. **Sociological**
   - Changing role expectations of patients
   - Diminishing information gap between physicians and patients

2. **Historical**
   - Development in medicine offers more (empirically validated) „ equipoise“ treatment options

3. **Ethical**
   - Patients have interest and right to be involved in medical decisions

4. **Empirical**
   - Research results are pushing for stronger involvement
   - and...
Regional variation (in Germany)

Faktencheck Gesundheit
BertelsmannStiftung

VARIATION UND VERTEILUNGSGERECHTIGKEIT

Patientenpräferenzen berücksichtigen

Unangemessene Variationen bei der Erbringung medizinischer Leistungen sollten reduziert werden. Überprüft werden müsste, ob sich US-amerikanische Erfahrungen auf das deutsche Gesundheitswesen übertragen lassen.

Dominick L. Frosch, Martin Härter, Daniela Simon, Albert G. Mulley, Jr.

Deutsches Ärzteblatt | Jg. 107 | Heft 43 | 29. Oktober 2010

Quelle: IGES; Destatis; Bundesamt für Kartographie und Geodäsie

2011/2012
Patient involvement in Germany

**Micro-level**
- Research network SDM 2001-2007 (BMG)
- Research activities 2008-2014 (BMBF)

**Meso-level**
- Sponsoring of patient counseling institutions
- Sponsoring of self help institutions
- Agency for Quality in Medicine (ÄZQ)
- Institute for Quality and Efficiency (IQWiG)

**Macro-level**
- New health law (2002) and patients’ right law (2012)
- Patients’ rights charta (2004)
- Government’s commissioner for patients (2004)
- Federal Joint Committee (with patient representatives)
“Shared decision-making is an approach where clinicians and patients make decisions together using the best available evidence. Patients are encouraged to think about the available screening, treatment, or management options and the likely benefits and harms of each so that they can communicate their preferences and help select the best course of action for them. Shared decision-making respects patient autonomy and promotes patient engagement”.

Patient-centred care

- Patient as person
  - Disease and illness experience

- Bio-psychosocial perspective
  - Whole person

- Common ground

- Patient-doctor relationship
  - Sharing power and responsibility
  - Therapeutic alliance

Research into SDM

Research domains (adapted from O’Connor, 2011)

1. Definition
2. Measurement
3. Interventions to promote SDM
4. Implementation in routine practice
SHARED DECISION-MAKING IN THE MEDICAL ENCOUNTER: WHAT DOES IT MEAN? (OR IT TAKES AT LEAST TWO TO TANGO)

CATHY CHARLES, AMIRAM GAFNI and TIM WHELAN

'Department of Clinical Epidemiology and Biostatistics, McMaster University, Hamilton, Ontario,

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Research into SDM

Research domains (adapted from O’Connor, 2011)

Definition → Measurement → Interventions to promote SDM → Implementation in routine practice

Extensive conceptual work, e.g.,
- Integrative model of SDM (Makoul & Clayman, 2006)
- Deliberation and determination (Elwyn & Miron-Shatz, 2009)
- Steps SDM process (Härter et al., 2004, 2008)

1. Disclosure that a decision needs to be made
2. Formulation of equality of partners
3. Presentation of treatment options (“equipoise”)
4. Informing on the benefits and risks of the options
5. Investigating the patient’s understanding and expectations
6. Identification of both parties’ preferences
7. Negotiation
8. Reaching a shared decision
9. Arrangement of follow-up
Measurement of shared decision making – a review of instruments

Isabelle Scholl1,*, Marije Koelewijn-van Loon2, Karen Sepucha3, Glyn Elwyn4, France Légare5, Martin Härter1, Jörg Dirmaier1

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2CAPHRI School for Public Health and Primary Care, Department of General Practice, Maastricht University, the Netherlands
3Health Decision Sciences Center, Massachusetts General Hospital, Harvard Medical School, Boston, USA
4Department of Primary Care and Public Health, School of Medicine, Cardiff University, UK
5Research Centre of Centre Hospitalier Universitaire de Québec, and Department of Family Medicine and Emergency Medicine Université Laval, Québec, Canada
# Shared Decision Questionnaire (SDM-Q-9)

<table>
<thead>
<tr>
<th>Language versions completed:</th>
<th>Ongoing translations:</th>
</tr>
</thead>
<tbody>
<tr>
<td>German</td>
<td>Korean</td>
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<tr>
<td>Dutch</td>
<td>Malaysian</td>
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<tr>
<td>English</td>
<td>Norwegian</td>
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<td>French (Canada)</td>
<td>Persian</td>
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<td>Hebrew</td>
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<td>Italian</td>
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<tr>
<td>Japanese</td>
<td></td>
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<tr>
<td>Spanish</td>
<td></td>
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</tbody>
</table>

**Vragenlijst Over Gezamenlijke Besluitvorming**

**Cuestionario sobre la toma de decisiones compartida**

**共有決定度 (シェアド ディシジョン メイキング) 質問紙 患者版**
Triangulation of perspectives

OPTION Scale

SDM-Q-Doc

SDM-Q-9

r=.32**

r=.19

r=.25**

Similar results, e.g., [1-4]

Research into SDM

Research domains (adapted from O’Connor, 2011)

- Definition
- Measurement
- Interventions to promote SDM
- Implementation in routine practice

Reviews revealed challenges:
(Elwyn et al., 2001; Dy, 2007; Légaré et al., 2007; Simon et al., 2007; Scholl et al. 2011)

- No extensive psychometric testing for many scales
- No standard outcome measures → low comparability of results
- Multiple perspectives: observation measures vs. perception of patient or clinician → triangulation of perspectives needed
Transfer strategies

• Training and CME activities for clinicians
  – to reinforce specific communication and SDM competencies

• Development of decision support tools and decision aids
  – to improve patient information and health literacy

• Training of patients
  – to prepare for stronger involvement
Online-Inventories

http://decisionaid.ohri.ca/

Englisch: ca. 350
Effectiveness of SDM

Clinicians:
- satisfaction with patient consultation
- evaluated patient information
- considered treatment options
- duration of consultation

Patients:
- knowledge, expectation about adv./disadvantages
- satisfaction with patient consultation
- satisfaction with decision made
- correct risk perception
- communication with clinician
- coping
- adherence/compliance (?)
- clinical outcomes / cost of care (?)
- decisional conflict
- passive and undecided


Stacey, D. et al. (2011). *Decision aids for people facing health treatment or screening decisions*. Cochrane Database of Systematic Reviews, 1.
Developed

- Multiple sclerosis (booklet)
- Breast cancer (booklet)
- Depression (booklet)
- Schizophrenia (booklet)
- Fibromyalgia (web-page)
- Cardiovascular risk and prevention („arriba“)

Interactive patient information systems

- Acute low back pain, Depression (TK, closed)
- Diabetes mellitus, Chronic back pain (2012, public domain)
- Adaptations (e.g. Prosdex) (AOK)
- Mental disorders (Psychosis, somatoform dis., etc.)

Web-based health informations (see IQWiG/AQM)

- All kind of issues (text)
<table>
<thead>
<tr>
<th>Year</th>
<th>Development</th>
<th>Implementation</th>
<th>Medical Education</th>
<th>Adaptation</th>
<th>Individualized Training</th>
</tr>
</thead>
<tbody>
<tr>
<td>2001</td>
<td>2 RCTs using patient reported outcomes (depression, fibromyalgia)</td>
<td>• &gt; 500 physicians &amp; 100 facilitators • publication of training manual + DVD</td>
<td>• ~ 50% of the 36 German medical schools teach SDM, using varying teaching materials</td>
<td>• breast &amp; colon cancer • cluster-RCT using patient reported and objective measures (OPTION)</td>
<td>• RCT individual coaching vs. e-learning module</td>
</tr>
</tbody>
</table>

Härter et al. (2011), Loh et al. (2007), Bieber et al. (2007, 2011)
Review

Training health professionals in shared decision-making: An international environmental scan

France Légaré a, Mary C. Politi b, Renée Drolet a, Sophie Desroches a, Dawn Stacey c, Hilary Bekker d
the SDM-CPD team 1

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b Health Communication Research Laboratory, George Warren Brown School of Social Work, Washington University in St-Louis, MO, USA
c School of Nursing, Faculty of Health Sciences, University of Ottawa, Ottawa, ON, Canada
d Leeds Institute of Health Sciences, School of Medicine, University of Leeds, Leeds, United Kingdom
Quo vadis?

- **Interprofessional**
  - health care system, teams

- **International**
  - international standards

- **Integrative**
  - e.g. Hamburg reform curriculum
## Communication competencies - reform curriculum UKE

### Learning cycle

<table>
<thead>
<tr>
<th>Step</th>
<th>Modules</th>
</tr>
</thead>
<tbody>
<tr>
<td>Step I</td>
<td>Basic skills in communication + basic knowledge</td>
</tr>
<tr>
<td>Step II</td>
<td>Shared decision making, Behavior change counseling - MI, Breaking bad news</td>
</tr>
<tr>
<td>Step III</td>
<td>Communication in palliative situations, Communication with migrants and difficult patients, Intra- and interprofessional communication</td>
</tr>
</tbody>
</table>
Research domains (adapted from O’Connor, 2011)

- Definition
- Measurement
- Interventions to promote SDM
- Implementation in routine practice
How to implement decision support?

• Changing clinicians’ attitudes → integration in medical schools and residency programs (Legaré et al, 2011)

• Integration in care pathways

Elwyn, Laitner et al, 2010
Amniocentesis
An amniocentesis gives you information about whether or not your unborn baby has a chromosome related problem. Use this grid to help you, your partner and your clinician decide whether or not to have this test.

<table>
<thead>
<tr>
<th>Frequently asked questions</th>
<th>Having amniocentesis</th>
<th>Not having amniocentesis</th>
</tr>
</thead>
<tbody>
<tr>
<td>Will we find out for definite if our unborn baby has Down’s syndrome?</td>
<td>Yes, amniocentesis will give you a definite answer. It is normally done around week 15 of your pregnancy.</td>
<td>No. The mid-pregnancy ultrasound scan can show if your child has a physical problem, but you will not know for definite about Down’s syndrome.</td>
</tr>
<tr>
<td>Will we find out if our unborn baby has another condition?</td>
<td>Amniocentesis can also detect some other chromosome problems but a normal amniocentesis result cannot rule out other chromosome problems.</td>
<td>The mid-pregnancy ultrasound scan may show some problems with the baby’s physical development, such as cleft lip, but will not tell you about chromosome related problems.</td>
</tr>
<tr>
<td>Are there any risks to the baby?</td>
<td>About 1 in 100 women who have an amniocentesis will miscarry. This risk is in addition to the usual risk of miscarriage for women at this stage of pregnancy, which is about 1 in 100. Having an amniocentesis increases the risk to 2 in 100</td>
<td>There are no additional risks to the pregnancy from not having an amniocentesis. The usual risk of miscarriage for all women at this stage of early pregnancy is about 1 in 100.</td>
</tr>
<tr>
<td>Are there any other risks?</td>
<td>A serious infection happens in about 1 in a 1000 amniocentesis procedures. Infection can lead to the baby being born early.</td>
<td>No. Not having an amniocentesis means that there are no added risks to the pregnancy as a result of this test.</td>
</tr>
<tr>
<td>If a problem is found, what does it mean for us?</td>
<td>You will have to decide whether to continue or end the pregnancy. You will be supported</td>
<td></td>
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<tr>
<td>Nr.</td>
<td>Sub-project title</td>
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<td>-----</td>
<td>--------------------------------------------------------</td>
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</tr>
<tr>
<td>1</td>
<td>Awareness and education about mental illness</td>
<td></td>
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<tr>
<td>2</td>
<td>Development of an interactive internet portal</td>
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<tr>
<td>3</td>
<td>Occupational health management</td>
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<td>4</td>
<td>Self management in GP care</td>
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<tr>
<td>5</td>
<td>Self help and family help with long-term mental illnesses</td>
<td></td>
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<tr>
<td>6</td>
<td>Health network psychosis</td>
<td></td>
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<tr>
<td>7</td>
<td>Health network depression – stepped care</td>
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<tr>
<td>8</td>
<td>Health network “somatoform and functional disorders (Sofu-Net)”</td>
<td></td>
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<tr>
<td>9</td>
<td>Health network “anorexia and bulimia nervosa”</td>
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<tr>
<td>10</td>
<td>Addiction illnesses in adolescence</td>
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<tr>
<td>11</td>
<td>Methodological quality assurance and evaluation</td>
<td></td>
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</tbody>
</table>

Hamburg – Network for Mental Health

[Diagram showing five health networks: psychosis, depression, addictions, somatoform syndromes, anorexia and bulimia.]

- Occupational health
- Self-management in GP care
- Self-help and family help
- Communication platform and interactive internet portal
- Information and education
- Methodological advice and evaluation
Hamburg – Network for Mental Health

Target users

People affected of depression, addiction illnesses, psychosis, somatoform syndroms, anorexia and bulimia etc.

Components of the Internet portal

» Module A: networking with others (social media community)
» Module B: self help programmes (e-health approaches)
» Module C: self rating / screening possibilities
» Module D: search / skype function for treatment / care offers
» Module E: information / decision tools for mental disorders
Current state of research in SDM

Research domains into SDM (adapted from O’Connor, 2011)

Definition

- still much to do
- international collaboration needed

Measurement

Interventions to promote SDM

- most work on PtDAs (not much in Germany)
- more research needed regarding clinician and patient training

Implementation in routine practice

- first steps in some countries
On the agenda to 2015

- High need for adaptation/development of evidence-based PtDS/DAs
  - *unclear, who will pay for it and will take the lead on it*

- Clarification of essentials and decision theories of DSIs, format of DSIs
  - *international cooperation and research*

- High need for high quality outcomes and instruments (e.g. patient involvement as a quality indicator for GCP)
  - *work in progress*

- Professional development / training / CME programs for clinicians
  - *international cooperation and research !!*
  - *unclear, who will invest to it (resident programs, chamber of physicians, part of the clinical exam?)*
International Shared Decision Making conferences (ISDM)

2001 Oxford (UK)
   Summer School
2003 Swansea/Wales (UK)
   New Conversations with Patients
2005 Ottawa (Canada)
   Implementing Shared Decision Making in Diverse Health Care Systems and Cultures
2007 Freiburg (Germany)
   Shared Decision-making in diverse Health Care Systems – translating Research into Practice
2009 Boston (USA)
   Shared Decision Making: from Vision to Reality
2011 Maastricht (Netherlands)
   Bridging the Gap between Research and Practice: Patient Pull or Clinician Push?
2013 Lima (Peru)
   Pacientes @ the Centre of Healthcare – globalizing Shared Decision Making
Thank you for your attention

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