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Citation: Hamann, J., Kohl, S., McCabe, R., Bühner, M., Mendel, R., Albus, M. & Bernd, J. (2016). What can patients do to facilitate shared decision making? A qualitative study of patients with depression or schizophrenia and psychiatrists. *Social Psychiatry and Psychiatric Epidemiology*, 51(4), pp. 617-625. doi: 10.1007/s00127-015-1089-z

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**What can patients do to facilitate shared decision making? A qualitative study
of patients with depression or schizophrenia and psychiatrists**

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Abstract

Purpose: Patient involvement in decision-making is endorsed by patients and professionals. While research has recently been conducted on how professionals can promote shared decision making (SDM), little is known about how patients can also facilitate SDM.

Methods: Seven focus groups were conducted: 3 with psychiatrists and 4 with patients with schizophrenia or depression. The focus groups were transcribed and independently coded line by line by 2 researchers. Data were analyzed using content analysis.

Results: Seven themes related to patient attitudes and behaviors were identified: honesty and openness with one's psychiatrist and oneself, trust in one's psychiatrist and patience with the treatment, respect and politeness, informing the psychiatrist and giving feedback, engagement/active participation during the consultation, gathering information/preparing for the consultation and implementing decisions. Barriers (e.g. avolition, lack of decisional capacity, powerlessness during involuntary treatment) and facilitators of active patient behavior were also identified.

Conclusions: There are various ways in which patients can facilitate SDM/play a more active role in decision making, with patients emphasizing being open and honest and psychiatrists emphasizing being active in the consultation. Interventions to increase active patient behavior may enhance SDM in mental health care.

Key words: shared decision making, patient autonomy, adherence, schizophrenia

Introduction

Shared decision-making (SDM) has attracted much attention in recent years in medicine, and also in mental health care [1; 2]. There is considerable evidence supporting patients' desire to participate in decision making [3] and also professionals' positive attitudes toward this [4; 5]. Implementing SDM in mental health has also been shown to be feasible (e.g. [6-8]). However, when observing communication between patients and doctors in mental health care, it becomes apparent that SDM does not routinely take place [9; 10].

While there has been a lot of research on the communicative behaviors of doctors that may facilitate SDM [11], the patient perspective has been rather neglected. The few publications that deal with patient behavior facilitating SDM report theoretical, prescriptive considerations [12]. There is, however, evidence on *patient activation*, an issue closely related to SDM. Here it has been shown that providing patients' with certain skills (e.g. asking questions, verifying information) can lead to more active involvement in decision making, better adherence or better health outcomes [13-15].

To date, there have been no studies of how patients may facilitate SDM in the field of mental health, especially in more acute settings, under circumstances that are possibly more restrictive compared to somatic medicine, due to reservations with regard to e.g. the patients' decisional capacity or the potential risk of self-harm [4; 5].

Methods

The aim of this study was to explore both patients' and psychiatrists' views on how patients can facilitate shared decision-making in acute mental health settings. As shared decision making is a joint activity between patients and doctors we conducted focus groups with both psychiatrists and patients.

Research team and reflexivity

The study was designed by a team of psychiatrists and psychologists familiar with the clinical treatment of mental health patients in acute settings. Focus groups were conducted and analyzed by two psychiatrists (JH, JB). The wider study team was consulted about the emerging analysis in regular meetings, where they reviewed the data and proposed coding categories and discussed areas of disagreement until consensus was reached.

Participants

Professionals were purposively sampled to include male and female psychiatrists, working either in inpatient or outpatient settings. Hospital psychiatrists and psychiatrists working in outpatient settings were recruited. Patients were purposively sampled to include male and female patients, with schizophrenia/schizoaffective psychosis (ICD 10: F20/F25) or depression/bipolar disorder (ICD 10: F31/F33) and with experience of both in- and outpatient treatment. To recruit patients, leaflets were distributed on psychiatric wards and respondents asked for their participation. Patients were aged between 18 and 65 years and capable of providing written informed consent. Patients were not eligible if they required an interpreter or had a learning disability.

Data collection

Data were collected within focus groups for which a topic guide was developed by the research team resulting in slightly different versions for professionals and patients.

Focus groups started with a general statement (“We want to discuss how patients and doctors can negotiate what kind of treatment is chosen”) and patients were requested to state their experiences and expectations as to how this goal could best be reached. As we expected especially physician-related factors to be discussed more prominently, we also asked specifically about patient based factors (“What can patients contribute so that you reach decisions that are reasonable and both patients and physicians can agree on?”). In case the question did not produce sufficient information, further clarification questions and prompts were used by the facilitators (e.g. “What else can patients do to contribute to successful treatment?”).

Focus groups were held separately for patients and psychiatrists and also separately for patients with depressive and psychotic disorders. Data were collected at the participating hospitals and at a private practice. Focus groups were led by one interviewer assisted by a second researcher. After conducting the 4 patient and 3 psychiatrist focus groups, it became evident that similar themes were discussed across the groups and as no new themes were emerging, no further groups were conducted.

Data analysis

All focus groups were audio-taped and transcribed verbatim. The transcripts were analyzed using content analysis, as described by Mayring [16]. All transcripts were independently coded line-by-line by two researchers (J.B., J.H.). These line-by-line codes were then discussed by the two researchers, which yielded 300 codes. Codes identified by one researcher and not the other were discussed and added when

consensus was reached, which resulted in more codes than either JB or JH had generated individually. Codes from all transcripts were thematically clustered to serve as the basis for higher level categories, of which there were 23. All codes were then grouped into these categories by the two researchers. The clustering of the 300 codes into 23 higher level categories were presented and discussed in four group meetings (J.B, J.H., R.M, M.B.). Also in these meetings, the 23 categories were further analyzed to identify seven higher order themes. Any areas of disagreement were resolved by group discussion until consensus was reached.

Ethics

The study received ethical approval from the Ethikkommission at the Technische Universität München.

Results

Seven focus groups were conducted (table 1): 4 groups were conducted with 16 patients (3-5 participants each), i.e. 2 groups with patients with psychotic disorders (coded as S1, S2..) and 2 groups with patients with depressive disorders (coded as D1, D2...); 3 groups were conducted with 21 physicians, i.e., 2 groups with hospital psychiatrists (coded as P1, P2,...) and 1 group with psychiatrists in private practice (coded as N1, N2, ...). All patients were hospitalized at the time of the interview and most had considerable experience of both in- and outpatient treatment (table 1).

In all groups, participants spontaneously began by discussing physician behaviors that facilitate SDM (e.g. *"It is most important to ask for all symptoms and to take a detailed history in order to obtain a full picture, to reach a diagnosis and also to explain the patient why this diagnosis is suggested"* P1). A number of directive questions were required before participants focused on patient behaviors.

In the following we present (I) the seven main themes of patient attitudes and behaviors that facilitate SDM, (ss patients and physicians showed high overall concordance we describe patients'/physicians' views together), (II) important differences between patients' and physicians' views, (III) barriers and facilitators of active patient behavior (contextual factors).

I. Main themes of patient attitudes and behaviors that facilitate SDM

Honesty and openness

Patients emphasized the need to speak openly about their condition and not to dissemble when talking to the doctor. This behavior was also thought to be essential

to guarantee that the patient's preferences can be addressed by the physician, because *"otherwise doctors do not know what really counts"* (D6). Also the physicians stressed the need to *„speak openly about feelings and fears“* (P8). In addition, they extended honesty and openness to issues such as talking about one's willingness or unwillingness (e.g. non-adherence) to engage in treatment. Another aspect emphasized by patients was "honesty" meaning not only openness towards the doctor but also being true to oneself, confronting the fact that one is suffering from a mental illness.

Trust and patience

Many physicians referred to patients' trust in their physicians as an important prerequisite for joint decision making. Here, statements ranged from blind trust to the recommendation *„to go to the hospital with an attitude that the other person (i.e. the doctor) is not intentionally planning to harm me"* (N7). Likewise patients emphasized that being patient, having some trust in advance and giving doctors and therapies a try might be helpful. Additionally, it was seen as necessary *„to be patient until drugs start working“* (S3).

Respect and politeness

Some psychiatrists felt that a lack of adequate or good manners often impedes shared decision making especially in the field of mental health. Thus, for example, the ability *„to let the other person finish her sentence“* (P8) is seen as a prerequisite before SDM can happen. Other issues raised were being punctual, knowing the doctor's name or being polite. Patients also addressed this issue and reported positive experiences when they abstained from being angry and treated their doctors politely.

Informing the doctor, giving feedback

This theme addressed all aspects of actively informing the doctor about oneself and one's current condition, of giving feedback regarding experiences with drug treatment but also of explicitly talking about being overwhelmed by the therapy or unhappy with the doctor-patient-relationship.

Patients and physicians emphasized that a detailed description of the patient's problem is an important first step in making decisions together. Moreover, giving feedback about experiences with medical treatment, especially regarding side-effects is seen as especially important. Finally, some patients and physicians saw it as helpful when patients give constructive criticism regarding interpersonal aspects, e.g. *"to tell the doctor, I feel hurt by you or not taken seriously"* (D3).

Engagement and active participation during the consultation

Engaging in decision making is, according to the interviewees (patients and psychiatrists), more than just giving feedback. Other behaviors in the consultation were also deemed necessary to facilitate SDM by patients and psychiatrists. These include becoming an expert about one's own illness and being competent in the consultation. Being competent means expressing treatment preferences, suggesting treatment options, taking the time necessary to deliberate about treatment decisions, and asking for explanations required to make informed decisions.

Gathering information and preparing for the consultation

Additional patient behaviors that take place outside the consultation, including gathering medical information and preparing for the consultation, were also identified as important.

This starts with selecting the right physician/psychiatrist because *“there are good and bad physicians, one has to pick those who treat you best”* (D4). Another important patient activity is becoming informed so that one is prepared for discussions with doctors.

Many psychiatrists advocate this behavior *„that somebody arrives with a certain knowledge, that you are able to discuss and argue“* (P6). Patients discussed a variety of possibilities where they could gather general information (e.g. about drugs on websites, in books etc.), but also identified the need to *“know how and with what drugs they had been treated earlier”* (S5). This information was seen as an essential prerequisite for SDM by psychiatrists. However, many patients and physicians stated that this information is often not known by patients.

Further, it was seen as helpful when patients prepare for consultations by either noting any thoughts, questions or requests they have or by organizing support (e.g. a relative who accompanies them).

Implementation and transfer

In this last theme, the need for adherence to and implementation of therapies was identified, again both by patients and psychiatrists. It was seen as vital that patients *„participate in all therapeutic offers, follow their doctors advice and try to implement”* (what has been decided) *“and to cooperate”* (S5).

II. Differences between patients and physicians regarding the main themes

There were no themes that were not mentioned by both patients and physicians. However, some differences in emphasis emerged between patients and physicians

(see table 2 last column). Patients were more likely to discuss the role of honesty and openness, informing and giving feedback to the doctor and implementing the agreed plan once it has been decided. On the other hand, physicians put more emphasis on patients being polite and respectful as many of them reported having experienced the opposite. In addition, more physicians than patients stressed the importance of patients preparing for consultations and the need for patients actively participating in the consultation.

III. Barriers and facilitators of active patient behavior

During the interviews many barriers and some facilitators for active patient behavior were discussed. These factors were categorized into physician factors, patient factors and setting factors (see table 3).

Physician factors

Many physicians spontaneously reflected on their own self-concept regarding how they interact with patients. This ranged from an *„attitude that I see the person coming to my practice as a partner, that I start talking with this person in an emancipated, non-hierarchical manner to first get an idea about what is actually going on“* (N7) to more paternalistic attitudes, like *”It’s like having a leaking water-tap at your home – you send for a plumber. You would expect the plumber to tell you what is needed“* (P4). In addition many psychiatrists quoted specific approaches they use during consultations such as *„listening without having a plan in mind“* (N7) or an *„open attitude“* (N8).

Patient factors

In this category were important aspects that influence the emergence of SDM beyond the aforementioned concrete patient-based behaviors. Especially from the physicians' side, the issue of the patients' ability to participate in decision making was frequently cited. Here, many psychiatrists see limited decisional capacity, especially in patients with schizophrenia, as an important barrier to SDM. Decisional capacity was often seen as impaired by a lack of insight, but also by thought disorders that were manifest in some of the focus groups. In contrast, experience with mental illness (e.g. having an illness for many years) was seen as a facilitator of SDM.

Many patients emphasized that mental illness often reduces their desire to participate in decision making which then results in passive behavior and paternalistic decision making. In particular, depressive symptoms were identified as important by patients as well as psychiatrists.

Psychiatrists mentioned that many patients in psychiatry have only a limited interest in any aspect of their treatment. On the contrary many patients, especially those with schizophrenia, reported experiences of powerlessness in psychiatric hospitals when their own and the psychiatrists' ideas about mental illness were different. These experiences of powerlessness with psychiatrists who can use coercion may deter patients, even many years later, to express their ideas and preferences when talking to their doctors.

Finally, some patients were reported – by psychiatrists - to induce a more participatory behavior in their psychiatrists than others. This includes verbal and non-verbal patient behavior, emotional stories or problems of particular interest.

Setting and other context factors

This category includes other factors that are related to the therapeutic setting or other contextual factors, outside the doctor-patient-interaction. Many psychiatrists

emphasized that decision making in acute treatment settings (i.e. closed wards, involuntary admission) is distinctly different from e.g. long-term outpatient treatment. This category overlaps to some extent with patient factors (insight etc.) but includes other aspects that cannot be influenced by patients such as the general atmosphere on a psychiatric ward.

Time constraints were seen as an important barrier to SDM by both patients and physicians. While patients acknowledge the high workload of physicians and often accept this as a limitation to more extensive discussions, many psychiatrists see a directive style of decision making as a possibility to save time. On the other hand, psychiatrists regret that time constraints hinder them from making more extensive attempts to foster active patient behavior or more mutual decision making.

Discussion

This study found that, according to both patients and psychiatrists, patients can do a lot to facilitate SDM and there is considerable agreement between patients and psychiatrists as to what attitudes and behaviors facilitate joint decision making. Both parties concur in their endorsement of active patient behavior and the necessity of patients and doctors making decisions together.

Seven themes were identified: honesty and openness, trust and patience, respect and politeness, informing the doctor and giving feedback, engagement and active participation during the consultation, gathering information and preparing for the consultation, and finally implementing what has been decided.

Regarding facilitators and barriers of these patient behaviors, most relate to the specific illness. Overall, there seems to be a lot of variation regarding the extent of active patient behavior actually taking place in clinical practice.

How do the findings fit with existing research?

In 1999, Towle and Godolphin [12] presented a prescriptive, “preliminary” list of “competencies for patients for informed shared decision making” that in many areas overlap with the categories empirically derived in our study (e.g. “Find a physician and establish, develop, and adapt a partnership”, “Articulate health problems”, “Access information”). On the other hand, there are some themes found in our study that were not suggested by Towle and Godolphin and vice versa. The more technical aspects of SDM (e.g. “Evaluate information”) were not raised by the interviewees in our study, while some of the apparently paternalistic categories in our study (e.g. trust and patience, respectfulness and politeness) are not reflected in those of Towle and Godolphin.

In the more general literature on patient-clinician-communication, aspects of patient *activation* tend to be emphasized. This includes active patient behaviors such as providing information, asking questions and preparing for consultations [17; 15], which are consistent with our categories “informing the doctor and giving feedback” and “engagement and active participation during the consultation”. Also the category “openness and honesty” is close to these communicative aspects and has also been judged as competent patient behavior in the consultation [18].

Several authors have already linked these aspects of patient-clinician-communication with actual decision making [19; 15].

The remaining categories “trust and patience”, “respectfulness and politeness” and “implementing the agreed” plan might be somehow specific for the experiences of patients with severe mental illness. Having experienced involuntary (or coercive) treatment, having perceived doctors as not on their side etc. may lead patients (and doctors) to see these “basic behaviors” with new eyes and attribute more importance to them than somatic patients and their physicians. In addition, many patients might have experienced that being too active (and not strategic enough) in the consultation may result in doctors becoming annoyed and more directive and being labelled as a difficult patient [20]. Therefore some patients might use politeness and honesty strategically to facilitate shared decision making.

Another issue might be the experience of a chronic, recurring, mental illness and the feeling that one is powerless to influence the course of illness. Here, trust and patience might have finally developed into a default strategy. Likewise, having experienced multiple relapses due to not taking antipsychotic/antidepressant drugs

might have led some patients to emphasize the need to adhere to treatment that has been prescribed.

Barriers and facilitators of SDM in mental health

Previous studies [21] have identified barriers that hinder physicians in performing SDM („I have no time for it“, „my patients don't want it“, “I already do it”). Our study now adds that one of these well-known barriers, time constraints, may also hinder active patient behavior. Moreover, mental health specific aspects also serve as potential barriers to active patient behavior. These include reduced decisional capacity or lack of interest in participation, both patterns often caused by depressive or negative symptoms or thought disorders. The association between negative symptoms and lower patient involvement in decision making has also been found in observational studies of shared decision making in mental health care [10].

Another very real barrier to SDM seems to be negative experiences with power used by psychiatrists such as involuntary admission or compulsory medical treatment. These experiences of powerlessness with psychiatrists, who have restricted patients in the past, have a long lasting effect. Even many years later, they prevent patients from expressing their ideas and preferences, so they feel they cannot participate in a truly collaborative way in these interactions.

Finally, physicians also often mentioned additional and rather implicit barriers that are not possible for patients to overcome such as the specific prevailing atmosphere on wards created by the staff, inpatient vs. outpatient treatment or the availability of consultation time.

Implications for clinical practice

This study has shown that specific patient behaviors may facilitate SDM in mental health care and are generally welcomed by psychiatrists. At the same time, there are significant barriers hindering patients from becoming more active. Ensuring meaningful SDM in mental health care suggests no longer neglecting the patients' side of SDM and emphasizing "competent" or "active" patient behavior and helping patients to overcome these barriers. In order to overcome these barriers, it must be emphasized that decisional incapacity is rather a state than a trait and may be addressed in training [22], that lack of interest in participation is often caused by negative experiences with physicians and may also be overcome by specialized intervention [19] and, finally, that active patient behavior may also be encouraged by specialized training [23; 24].

Thus, potential barriers that to date hinder patients from engaging in behaviors that facilitate SDM can be overcome if they are addressed in clinical care. Additionally helpful would be the thorough implementation of other, existing, measures such as psychoeducation and, a facilitative communication style on the part of mental health professionals, which in itself can encourage active patient behavior [9; 10].

Limitations

Potential limitations of this study include the relatively small sample size and the inclusion of rather ill and chronic patients, all of whom were currently under psychiatric treatment. The impact of e.g. experiences of coercive measures may be of less importance for patients with a more benign course of illness. Finally, the issue of decision making and patient facilitation of SDM is a complex one, requiring abstract thinking which might have been affected in some of the interviewed patients.

Conclusions

Mental health patients have a range of possibilities to facilitate and increase SDM. This patient related side of SDM has to date been neglected both in research and clinical practice. Focused interventions to support patients' decisional capacity, participation preferences and active behavior may considerably enhance SDM in mental health.

Acknowledgements: This study was funded by the German Ministry for Research and Education (Grant Number 01GX1049).

Conflicts of interest: On behalf of all authors, the corresponding author states that there is no conflict of interest.

References

1. Patel SR, Bakken S, Ruland C (2008) Recent advances in shared decision making for mental health. *Curr Opin Psychiatry* 21:606-612
2. Beitinger R, Kissling W, Hamann J (2014) Trends and perspectives of shared decision-making in schizophrenia and related disorders. *Curr Opin Psychiatry* 27:222-229
3. Hamann J, Neuner B, Kasper J, Vodermaier A, Loh A, Deinzer A, Heesen C, Kissling W, Busch R, Schmieder R, Spies C, Caspari C, Harter M (2007) Participation preferences of patients with acute and chronic conditions. *Health Expect* 10:358-363
4. Seale C, Chaplin R, Lelliott P, Quirk A (2006) Sharing decisions in consultations involving anti-psychotic medication: a qualitative study of psychiatrists' experiences. *Soc Sci Med* 62:2861-2873
5. Hamann J, Mendel R, Cohen R, Heres S, Ziegler M, Buhner M, Kissling W (2009) Psychiatrists' use of shared decision making in the treatment of schizophrenia: patient characteristics and decision topics. *Psychiatr Serv* 60:1107-1112
6. Hamann J, Langer B, Winkler V, Busch R, Cohen R, Leucht S, Kissling W (2006) Shared decision making for in-patients with schizophrenia. *Acta Psychiatr Scand* 114:265-273
7. Loh A, Simon D, Wills CE, Kriston L, Niebling W, Harter M (2007) The effects of a shared decision-making intervention in primary care of depression: a cluster-randomized controlled trial. *Pat Educ Couns* 67:324-332
8. Stein BD, Kogan JN, Mihalyo MJ, Schuster J, Deegan PE, Sorbero MJ, Drake RE (2013) Use of a computerized medication shared decision making tool in

- community mental health settings: impact on psychotropic medication adherence. *Comm Ment Health J* 49:185-192
9. Goss C, Moretti F, Mazzi MA, Del Piccolo L, Rimondini M, Zimmermann C (2008) Involving patients in decisions during psychiatric consultations. *Br J Psychiatry* 193:416-421
 10. McCabe R, Khanom H, Bailey P, Priebe S (2013) Shared decision-making in ongoing outpatient psychiatric treatment. *Pat Educ Couns* 91:326-328
 11. Bieber C, Nicolai J, Hartmann M, Blumenstiel K, Ringel N, Schneider A, Harter M, Eich W, Loh A (2009) Training physicians in shared decision-making-who can be reached and what is achieved? *Pat Educ Couns* 77:48-54
 12. Towle A, Godolphin W (1999) Framework for teaching and learning informed shared decision making. *BMJ* 319:766-771
 13. Greenfield S, Kaplan SH, Ware JE, Jr., Yano EM, Frank HJ (1988) Patients' participation in medical care: effects on blood sugar control and quality of life in diabetes. *J Gen Int Med* 3:448-457
 14. Post DM, Cegala DJ, Miser WF (2002) The other half of the whole: teaching patients to communicate with physicians. *Fam Med* 34:344-352
 15. Alegria M, Carson N, Flores M, Li X, Shi P, Lessios AS, Polo A, Allen M, Fierro M, Interian A, Jimenez A, La Roche M, Lee C, Lewis-Fernandez R, Livas-Stein G, Safar L, Schuman C, Storey J, Shrout PE (2014) Activation, self-management, engagement, and retention in behavioral health care: a randomized clinical trial of the DECIDE intervention. *JAMA Psychiatry* 71:557-565
 16. Mayring P (2010) *Qualitative Inhaltsanalyse. Grundlagen und Technik*. Beltz Verlag, Weinheim und Basel

17. Cegala DJ, Marinelli T, Post D (2000) The effects of patient communication skills training on compliance. *Arch Fam Med* 9:57-64
18. Farin E, Schmidt E, Gramm L (2014) Patient communication competence: development of a German questionnaire and correlates of competent patient behavior. *Pat Educ Couns* 94:342-350
19. Hamann J, Mendel R, Meier A, Asani F, Pausch E, Leucht S, Kissling W (2011) "How to speak to your psychiatrist": shared decision-making training for inpatients with schizophrenia. *Psychiatr Serv* 62:1218-1221
20. Hamann J, Mendel R, Buhner M, Kissling W, Cohen R, Knipfer E, Eckstein HH (2012) How should patients behave to facilitate shared decision making--the doctors' view. *Health Expect* 15:360-366
21. Legare F, Ratté S, Gravel K, Graham ID (2008) Barriers and facilitators to implementing shared decision-making in clinical practice: update of a systematic review of health professionals' perceptions. *Pat Educ Couns* 73:526-535
22. Carpenter WT, Jr., Gold JM, Lahti AC, Queern CA, Conley RR, Bartko JJ, Kovnick J, Appelbaum PS (2000) Decisional capacity for informed consent in schizophrenia research. *Arch Gen Psychiatry* 57:533-538
23. Cegala DJ, McClure L, Marinelli TM, Post DM (2000) The effects of communication skills training on patients' participation during medical interviews. *Pat Educ Couns* 41:209-222
24. Cegala DJ, Post DM (2009) The impact of patients' participation on physicians' patient-centered communication. *Pat Educ Couns* 77:202-208

Table 1: Participants

	Patients (N=16)	Physicians (N=17)
Age	M=41.8 (SD=14.6)	M=44.9 (SD=7.7)
Gender	8m 8 f	11 m 6 f
Diagnosis	Schizophrenia 7 Bipolar disorder 3 Major depression 6	/
Professional experience	/	M=15.3 (SD=6.4)

Table 2: Main themes of patients' facilitation of SDM

Main themes	Description	Exemplary quotes	Frequencies
Honesty and openness	To be honest and to frankly talk about one's complaints (not to dissimulate), otherwise doctors have no chance to work with patient's preferences. Also talk about one's willingness to engage in treatment or to disclose non-adherence. To be honest with oneself to reach treatment goals.	<i>"You ought to be honest and turn your inside out so that you finally receive help."</i> D5 <i>"It is important to report honestly whether you took the medication or not, and for what reason."</i> N5	Quotations from 12 patients (75%) and 9 physicians (43%).
Trust and patience	To be trusting or trust in advance. To give the doctors (and the therapies) a chance, to be open toward suggestions from the doctors. To be patient until therapies start working.	<i>"However the aim is optimal treatment. And therefore you primarily need trust in the physician."</i> P5 <i>"Yes, at least trying, sometimes you have a negative opinion on a therapy and then you</i>	Quotations from 9 patients (56%) and 11 physicians (52%).

		<i>find out that after all it works, once attending and taking a look.” D2</i>	
Respectfulness and politeness	To show politeness and respect, even if patients disagree with disease models of their doctors. Being angry or impolite leads to directive doctor behavior.	<p><i>“Listening to each other, quite a normal basic-rule for communication. If the patient constantly interrupts me he will not find out what I am about to tell him and then the conversation will take another course. The whole issue starts with simple rules for communication.” P8</i></p> <p><i>“I had the experience that when communicating in a calm and normal manner without reproach there will be responding from the doctor. And finally it turns out to have been a misunderstanding.” D3</i></p>	Quotations from 2 patients (13%) and 6 physicians (29%).
Informing the doctor, giving	To actively inform the doctor about everything related to the complaints and	<i>“I always try to go into detail, even if the doctor does not want to know the whole lot at the</i>	Quotations from 10 patients (63%)

<p>feedback</p>	<p>the therapy. To give feedback regarding therapeutic effects and the relationship between patient and doctor.</p>	<p><i>moment. But actually everything is somewhat related, then I just say it, if he did not want to know that, well. But better once giving too much information. Especially in situations where it is relevant that there is an improvement I do not hold back anything.” S7</i></p> <p><i>“Otherwise I do not know what is in the interest of the patient if there is no response.” P2</i></p> <p><i>“Generally I welcome (patients) talking about ones’ experiences with a medication” N5</i></p> <p><i>„I would address side effects immediately.” (S3)</i></p> <p><i>“It is a positive experience when for example a depressed patient addresses that he was hurt</i></p>	<p>and 3 physicians (14%).</p>
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		<i>by a remark from me, the fact that he can speak out on it leads to an openness that contributes to a positive atmosphere in treatment.” N5</i>	
Engagement and active participation during the consultation	To take responsibility, to become and be competent, to take time for deliberation about therapeutic decisions, to have and express treatment preferences, to ask questions and to request explanations.	<p><i>“Oneself being an expert on one’s disease and symptoms.” D3</i></p> <p><i>„We want the brave (patient), the one taking responsibility, the active one.” P2</i></p> <p><i>“Thus lately I had a good experience when suggesting Dr. S. a medication myself that I wanted to try, instantly she was supportive” D3</i></p> <p><i>“I have read this and that, what do you think of it?</i></p> <p><i>Seeing me as a partner not merely as physician” P7</i></p> <p><i>“Having a question or wanting detailed</i></p>	Quotations from 7 patients (44%) and 12 physicians (57%).

		<i>information is possibly annoying but important!"</i> N6	
Gathering information and preparing for the consultation	To search for the right physician, to acquire information, to get a second opinion, to be informed about one's own illness and any treatment one has received, to prepare for the consultations, to organize support, to have an emergency plan.	<i>"Most patients do not know the names of their drugs and moreover what they were prescribed 10 or 20 years ago. That's a pity, in my opinion patients need to know, what has helped and what has not helped, what were triggers (for the disease) then and now"</i> D3	Quotations from 9 patients (56%) and 9 physicians (43%).
Implementation and transfer	To participate in therapy, to follow the doctor's advice, to be adherent.	See text.	Quotations from 10 patients (63%) and 7 physicians (33%).

Table 3: Barriers and facilitators of active patient behavior

<u>Main themes</u>	<u>Subcategories</u>	<u>Quotes</u>
Physician factors	Self-concept	<i>„The attitude that I see the person coming to my practice as a partner, that I start talking with this person in an emancipated, non-hierarchical manner to first get an idea about what is actually going on“ N7</i>
	techniques	<i>„listening without having a plan in mind“ N7</i>
Patient factors	Reduced decisional capacity (e.g. due to thought disturbances) or good capacity due to experience with the illness	<i>„It is probably a continuum between co-deciding and not being able to co-decide. It very much depends on the patients' skills, for example someone who is more educated, more sophisticated and capable of thinking intellectually might be able to take a complex decision involving a risk assessment in contrast to someone who cannot handle such information.“</i> <i>P3</i> <i>“Physicians also responding to and working with these issues, that we are not in the stupid 20s or 60s, where you could do research, but society was on the brink, and that means, that it is never like this, as accustomed, you</i>

		<p><i>just have to set higher, because we are in a technological era and worlds are forming which are against former feelings, that is something completely different". S4</i></p> <p>(Comment: this patient exhibits disorganized thought during the focus group)</p> <p><i>"I have been mentally unwell for thirty years now and I am very experienced. (...) When I was here in winter she left the issue of medication completely to me because she said you have been ill for thirty years now, you have so much experience with the medication, actually she fully trusted me." S3</i></p>
	<p>Reduced desire to participate in decision making</p>	<p><i>„Being depressed I did not want to know about anything and also did not want to talk to any doctor. I also was not interested in which therapy would have been helpful or adequate, that was not what I wanted. At the earliest after one week I was ready to answer questions and participate. But when I arrived I did not want to participate". D1</i></p>

	Experiences with powerlessness / diverging concepts of illness	<p><i>„I had bad experiences (with the medication) and then the doctor said well then we will take the depot and I said: No I do not want a depot! And then she just persuaded me and I had no choice.“ S4</i></p> <p><i>“I had absolutely no influence; they gave me the tablets and said: Open your mouth in order to see whether I had swallowed; whatever I would have done, they would have put it in anyway, without my agreement.” S6</i></p>
	sympathy	<p><i>“To tell the truth some patients get a sympathy bonus. The feelings I arouse in patients are also aroused the other way round. What I always do at first contact is to evaluate the basic mental personality. How does he respond to the conversation? Is he rather stubborn or curious- bright? Then I also fancy telling him something- he is interested, it depends on whether he is a patient I can connect with at the same level, that is rather the patient that spontaneously attracts me and of course there is sympathy involved.” P8</i></p>
Setting factors	In- vs. outpatient treatment	<p><i>“In private practice there are patients that are well suited to you, that differs between private practice and hospital”. N7</i></p>

	Atmosphere on wards	<p><i>“The actual atmosphere on the ward or also which staff is on the different wards or who is the primary nurse. There are many factors that the patient cannot influence.” P1</i></p>
	Bureaucracy and lack of time	<p><i>“I think physicians have too much bureaucratic work. I see them always carrying out some bureaucratic task rather than working with patients.” S2</i></p> <p><i>“Time just plays a decisive role. When proceeding directly I am finished more quickly with the patient and quicker reaching the aim, as soon as I leave a gap, give free space it will take more time. When having five new patients in night shift I will not engage in discussions but then I am also directive, convincingly playing the role and seeing that as little questions as possible come up, because possibly I just feel certain. When having more time I can arrange the conversation more freely”. P8</i></p>