Patient Preference and Adherence

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ORIGINAL RESEARCH

Identification and Rating of Treatment Goals in Schizophrenia: Delphi Process and Concordance Survey in Matched Physician-Patient Pairs

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Introduction: Ratings of treatment goals for patients with schizophrenia have been studied in both patients and physicians. However, in most studies so far, treatment goals were assessed either by psychiatrists or by patients, but not by both for an individual patient case. Therefore, our study assessed treatment goals from matched physician-patient pairs.

Methods: First, an expert panel created a questionnaire with treatment goals, based on a systematic literature search. These goals were rated for their relevance in the treatment of schizophrenia by 24 independent psychiatrists. In the second part of the study, questionnaires were sent to psychiatrists all over Germany. Psychiatrists were asked to rate treatment goals for up to 3 specific patients. Furthermore, these same patients were asked to rate the goals for themselves.

Results: In the first part of the study, the 24 psychiatrists agreed that 30 out of 31 treatment goals chosen by the expert panel were relevant. In the second part, effectiveness and quality of life were more often seen as the most important treatment goal categories than tolerability by both patients and physicians in matched pairs of 80 patients and 28 physicians. There was a substantial agreement between physicians and patients. However, patients expressed apprehension about possible side effects of the medication, a concern not recognized in its extent by physicians. Patients also prioritized treatment goals related to tasks of daily life and coping with illness, whereas physicians put greater emphasis on preventing relapses and re-hospitalizations.

Conclusion: We found that experts agree upon the importance of 30 treatment goals from three categories. Physicians and patients largely align on treatment goals. More emphasis may be placed on clarifying potential medication side effects. Physicians should be aware that patients' priorities could be more focused on improving quality of life and gaining autonomy rather than symptom management.

Keywords: Schizophrenia, treatment goal, patient centered, concordance

Introduction

Schizophrenia is a severe mental disorder characterized by heterogeneous symptoms, often showing a very individual course of illness for each patient.[1,2] Schizophrenia can severely affect psychosocial functioning[3] and areas of well-being and health-related quality of life.[4] Considering the heterogeneous symptomatology, many different treatment goals seem conceivable,[5] depending on the individual situation of every patient and the stage of the disease. For example, goals may differ in early vs chronic stage of the disease, or for acutely ill patients vs stabilized patients. Furthermore, the perception of the relative importance of the different treatment goals may differ between patients and physicians.[6–9] We recently

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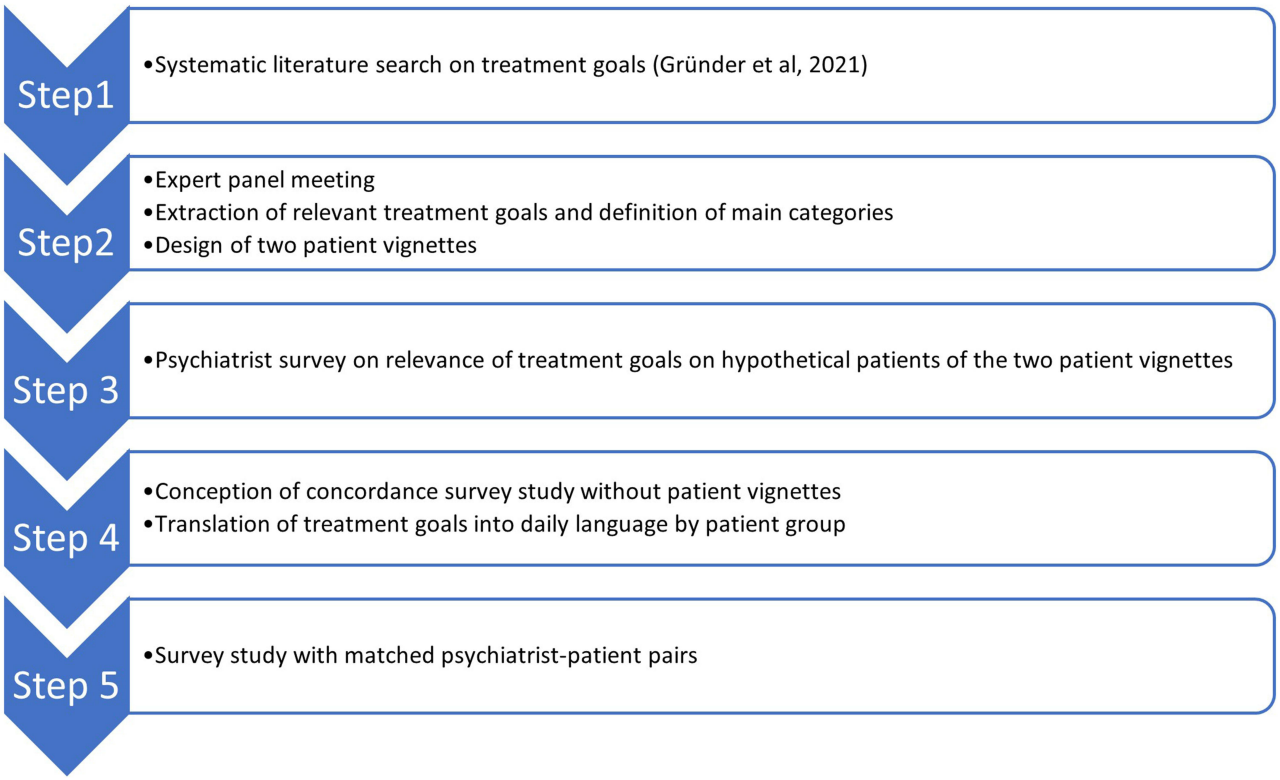

Figure 1 Overview on steps of the Delphi panel process and the concordance survey.

reviewed the literature on treatment goals and found that while physicians and patients largely agree on treatment goals, there is a trend towards treatment goals pertaining to well-being and health-related quality of life being more valued by patients, while physicians tend to focus more on "traditional" symptom- and functioning-related goals.[5] Furthermore, some studies have found subsets of patients with different priorities.[10,11] Available data so far usually describe concordance between patients and physicians on the group level, but not on the level of matched patient-physician pairs. The only exception, to our knowledge, is a report by Ascher-Svanum et al, who describe patient-level concordance values for reasons to continue or discontinue medication,[7] some of which are related to met or unmet treatment goals. They noted a high agreement between patients and physicians.

Here, we set out to study concordance of treatment goal valuations by matched physician-patient pairs. Our primary objective was to evaluate and prioritize treatment goals from a psychiatrists' and patients' perspective. The secondary objective was to compare treatment goals between psychiatrists and their patients.

Methods

This research work consisted of two distinct phases: The first part of the study comprised a Delphi panel process to establish expert consensus on relevant treatment goals in schizophrenia. The second part consisted of a survey in matched physician-patient pairs aiming to determine whether treatment goals perceived by patients and those that their physicians envision for these patients match.

Figure 1 provides a brief overview of the steps undertaken during the first (steps 1 to 3) and the second part of the study (steps 4 and 5).

Step 1: Identification of Possible Treatment Goals in the Literature

We performed a systematic literature search in PubMed, the details of which are published in Gründer et al, 2021.[5] Briefly, we searched for literature on treatment goals for patients with schizophrenia from the patient perspective, physician perspective, or both. This included original studies and reviews.

Step 2: Selection of the Most Relevant Treatment Goals by an Expert Panel

First, we created a list of treatment goals using the Delphi method. The Delphi panel method was introduced in the 1950s by Norman Dalkey and Olaf Helmer.[12] The Delphi process has been developed mainly to make prognoses, especially in cases where evidence is lacking. During the process, facilitated by a moderator, expert opinions are gathered, potentially in multiple rounds, with feedback of the results of previous rounds until consensus is reached.[13] By taking this, an estimate can be made, even in a state of uncertainty.

We set up multiple rounds for the Delphi process:

In the first round of the Delphi process, all identified treatment goals were presented to an expert panel. The panel consisted of six psychiatrists working in clinical or private practice settings (Gerhard Gründer, Karolina Leopold, Michael Paulzen, Stefanie Schell, Katharina Stengler, Stefan Leucht) and one psychologist (Stefan Klingberg). The experts were selected based on their expertise in the field of treating patients with schizophrenia. They should have a diverse academic background and be involved in both inpatient and outpatient treatment.

The expert panel met two times to allow for extensive discussion: there was an in-person meeting in Frankfurt am Main in January 2020, and a telephone conference in February 2020. In a discussion involving the whole group, the experts extracted the treatment goals which they deemed most relevant, came up with three main categories of treatment goals, and designed two patient vignettes that described hypothetical patients. These were created to test whether some goals were only relevant for a subset of patients or whether they could be generalized. The vignettes described two hypothetical patients with different characteristics (young vs middle-aged, recent onset vs chronic schizophrenia, still in education/training vs retired). The patient vignettes were deliberately vague to prompt physicians to recall patients who they actually see.

Patient Vignette 1

Patient (m/f), early 20s, first psychotic episode one year ago (fully remitted), currently second episode after partnership crisis and attempt to discontinue medication. Positive symptoms improved under initial therapy, slight negative symptoms and cognitive disturbances. Cannabis use. Medication side effects. Partnership continues, studies/training interrupted due to illness. Self-deprecation due to the diagnosis.

Patient Vignette 2

Patient (m/f), mid-40s, first episode in early adulthood with diagnosis of paranoid schizophrenia (ICD 10: F20.0). Multiple episodes with productive psychotic symptoms and inpatient stays. Current persistent productive symptomatology and negative symptomatology as well as cognitive deficits. Patient lives alone and receives outpatient psychiatric care. Patient is retired due to illness. Somatic comorbidities and medication side effects are present. Patient is a smoker. Originally worked as a craftsperson, traumatizing experience in childhood, close relationship to core family, single, no children. Few hobbies. Currently on continuous antipsychotic therapy and concomitant medication.

Step 3: Consensus Development on the Selected Goals by a Larger Group of Experienced Physicians

In the second round of the Delphi process, questionnaires were sent out via mail to psychiatrists, asking them to indicate if they consider the three main categories of treatment goals relevant, and if they consider each individual treatment goal relevant for the hypothetical patients described in the vignettes. Rating was done on a Likert scale made up as follows: 1 – Fully disagree, 2 – Disagree, 3 – Rather disagree, 4 – Rather agree, 5 – Agree, 6 – Fully agree. Questionnaires were sent out to a random sample of 126 physicians. Additionally, 48 questionnaires were handed out to physicians at a scientific panel (a continuing education event for psychiatrists), so that a total of 174 questionnaires were distributed. Answers were collected until 11 November 2020.

Step 4: Conception of Concordance Survey Study

For a concordance survey between matched patient-psychiatrist pairs on the treatment goals identified and agreed on during the Delphi process, all treatment goals were translated into everyday language by a specifically selected patient group.

Step 5: Concordance of Matched Patient-Physician Pairs on Treatment Goals

In the second part of the study, we assessed how matched patient-physician pairs evaluated the treatment goals. The aim of this survey was to verify the questionnaire and items chosen from a psychiatrist and patient perspective in daily routine and compare the outcome for similarities and differences between the groups (psychiatrists vs patients).

The survey was conducted in psychiatric outpatient clinics, hospitals and among psychiatrists in a private practice in Germany between October 2022 and July 2023. The clinical research organization contacted 2003 psychiatrists via mail. We aimed to involve 45 psychiatrists and 135 patients in the survey, considering the feasibility of this survey in routine medical practice, in order to obtain a patient clientele representative of the clinical picture.

We asked each participating physician to document treatment goals for a maximum of 3 patients. The physician selected suitable patients with a diagnosis of schizophrenia according to the ICD-10 criteria. The physician informed the selected patients verbally and in writing about the purpose and procedure as well as other details (including data protection) in connection with the interview. The patient was given a patient information leaflet containing all relevant considerations and, after an appropriate reflection period, gave written consent to participate.

Inclusion criteria were a diagnosis of schizophrenia according to ICD-10, being adult and giving written informed consent. There were no exclusion criteria for this study. The survey was presented to the International Medical and Dental Ethics Commission IMDEC, Freiburg, resulting in a positive vote.

The survey was conducted during a routine visit of the patient. The physician filled in a "Questionnaire for the physician" on what they considered to be the important treatment goals for a particular patient. The physician then asked the particular patient to complete the "Questionnaire for the patient" on the treatment goals that were important from their point of view. It was noted if assistance, eg by a nurse, was necessary. The completed questionnaire was placed in an envelope by the patient and the envelope was then sealed. The physician completed the "Data sheet for the patient". The three documents formed one survey unit.

Participating physicians were financially compensated for their time to fill in the questionnaires. Patients did not receive any compensation.

Statistical Analysis

All assessment data, including demographics, were summarized using descriptive techniques. Summary statistics (mean, standard deviation, median, minimum and maximum values) were presented for continuous variables. Counts and percentages were presented for categorical and binary variables.

Inferential statistical methods were used to compare the responses of patients and psychiatrists. As far as statistical tests were calculated, they had exploratory character and did not serve the confirmatory test of hypotheses formulated before the investigation. No alpha adjustment was therefore performed. When assessing the results of inferential statistical tests and calculating confidence intervals, a 5% probability of error was used as a basis. Data processing and statistical analysis were performed using the SAS program system (SAS version 9.4, SAS Institute Inc., Cary, NC).

Treatment goals were assessed by identifying the most important, and additionally the second and third most important treatment goals in each of the three categories of effectiveness/symptom reduction, tolerability and quality of life/functioning/participation. Additionally, all treatment goals were to be rated "most important", "also important", "less important" or "hardly important". These ratings were transformed into numbers (1 to 4) and mean ratings were calculated for each treatment goal. Mean ratings were compared between physicians and patients using the Wilcoxon signed rank test. Ratings of symptoms were also shown graphically using spider charts with grade 4 (hardly important) in the center and grade 1 (most important) on the outside. Symptoms can therefore be compared between each other and also between physicians and patients with marks residing more on the outside meaning a higher importance.

Results

Part 1: Choice of Treatment Goals via a Delphi Process

Step 1: Identification of Possible Treatment Goals From the Literature

Details of the literature review have been published in Gründer et al, 2021.[5] Briefly, a PubMed search performed on February 3rd, 2020 produced 882 hits, which were screened for treatment goals. Out of these, 44 full-text records

with information on treatment goals in schizophrenia were identified. Additionally, 8 records were added that were identified from reference lists. Therefore, treatment goals were extracted from a total of 52 full-text articles (44 original articles and 8 reviews). The full list of extracted treatment goals can be found in the supplement of Gründer et al, 2021.[5]

Step 2: Selection of the Most Relevant Treatment Goals by an Expert Panel

The full list of extracted goals was presented to a panel of 7 experts. All experts worked at clinics, 6 of them at a university hospital. Their mean clinical experience was 24 years, and the mean experience as a consultant in psychiatry was 18 years. They extracted the most important treatment goals from the list of all found treatment goals. The goals were then grouped into three main categories: effectiveness/symptom reduction (12 goals), tolerability (8 goals), and quality of life/functioning/participation (11 goals). The goals are shown in Table 1.

Table 1 Treatment Goals Selected by the Expert Panel

Category Effectiveness/Symptom Reduction
Reduction of perceptual distortions (hallucinations)
Reduction of delusions (fear of persecution, observation, manipulation, being influenced)
Decrease in irritability/hostility/aggressiveness
No self endangerment
Clear thinking
Good concentration/learning capacity/attention
More motivation/more drive/more energy/less exhaustion
Mood improvement
Reduction of anxiety/uncertainty
Being able to feel emotions
Being able to enjoy
Reduction in relapses/hospitalizations/medical interventions
Category tolerability
No weight gain or the least amount of weight gain possible
No or the lowest possible level of restlessness/agitation
No or the least amount of fatigue/slowing down possible
Not feeling subdued
No metabolic disturbances or the lowest level possible (eg, hyperglycemia)
No hormonal disturbances or the lowest level possible (eg, prolactin elevation)
No sexual dysfunction or the least amount of sexual dysfunction possible
No or the lowest possible degree of cardiac dysfunction/other organ dysfunction

(*Continued*)

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Table 1 (Continued).

Category quality of life/functioning/participation
Improving work-related skills and competencies (school/study/job)
Ability to establish and maintain close relationships (family, children, friends, intimate relationships)
Regaining and maintaining abilities to manage activities of daily life (housing, finances)
Self-care skills (nutrition, hygiene, clothing, physical health)
Maintenance of self-determination/autonomy
Satisfaction with the current life situation
Self-confidence/assertiveness/standing up for convictions
Reduction of self-stigmatization (thinking oneself less valuable because of the disease)
Being able to pursue a hobby/leisure activities
Disease control without medication
Make sufficient use of health care services for concomitant somatic and psychiatric diseases

Step 3: Consensus Development on the Selected Goals by a Larger Group of Experienced Physicians

A total of 174 questionnaires were distributed. Answers from 24 physicians were obtained (13.8%). Their mean clinical experience in psychiatry was 16.8 years (psychiatrists only, n = 22). Sixteen physicians worked in a resident practice, 8 in a clinic. The mean clinical experience was 25 years, the mean experience with patients with schizophrenia was 21.5 years.

Rating of Categories

Ratings of importance were only marginally different between categories as well as between patient vignettes (Figure 2).

Rating of Separate Treatment Goals in Each Category

Physicians were asked, "Would you attribute a high importance to these treatment goals when making a treatment decision?"

The relevance of all presented treatment goals was rated as high, with ratings mostly between 5 (agree) and 6 (fully agree) for both patient vignettes (Supplementary Figures 1–3). Slightly more relevance was seen within the mentioned range concerning

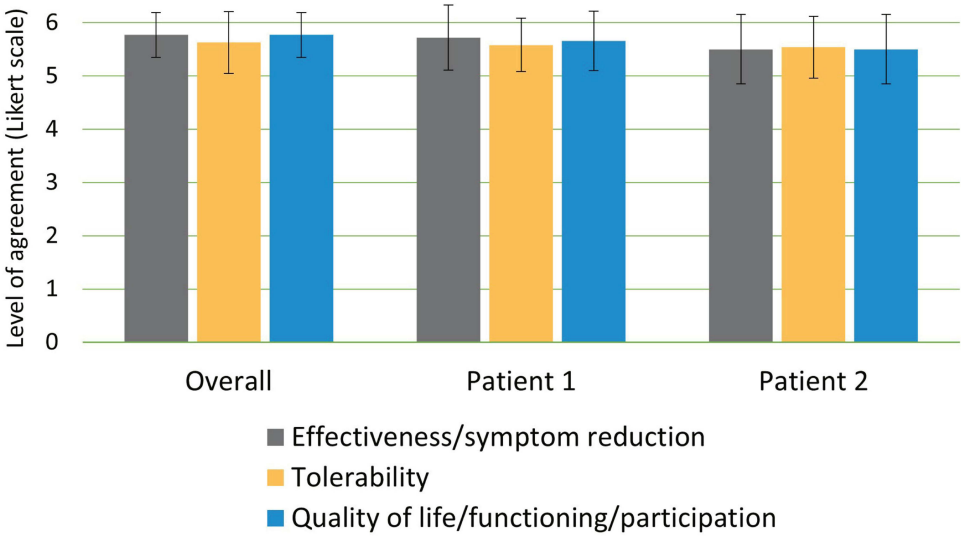

Figure 2 Level of agreement on the importance of treatment goal categories. 1 – Fully disagree, 2 – Disagree, 3 – Rather disagree, 4 – Rather agree, 5 – Agree, 6 – Fully agree. Error bars represent standard deviations.

"no self endangerment" for both patient vignettes, "reduction in relapses/hospitalization/medical interventions" for vignette 1, and "clear thinking" for vignette 2. Only for patient vignette 2, a level of at least 5 was not reached in the effectiveness goals "good concentration/learning capacity/attention", "being able to feel emotions" and "being able to enjoy". The level of agreement was a bit higher than 5 for all the tolerability goals (Supplementary Figure 2). The tolerability goal considered most important by the experts was "no or the lowest possible degree of cardiac dysfunction/other organ dysfunction".

In the quality of life/functioning/participation category, the perceived importance level was also predominantly between 5 and 6 (Supplementary Figure 3). However, there was an exception in the goal "improving work-related skills and competencies (school/study/job)" in patient vignette 2 with a mean of 4.32 ± 0.97. A level of around 3 (rather disagree; vignette 1: mean 3.27 ± 1.17; vignette 2: mean 2.77 ± 1.44) was seen for the objective "disease control without medication".

Step 4: Conception of Concordance Survey Study

As a result of step three, the two patient vignettes were disregarded for the design of the concordance survey in matched patient-physician pairs. The reason for that was a lack of clear differentiation between a younger patient experiencing their second episode and an older patient with a history of multiple episodes. However, all treatment objectives were incorporated into the concordance survey, as the expert panel had assigned importance to each of them.

Step 5: Concordance of Matched Patient-Physician Pairs on Treatment Goals

We obtained data from 80 matched physician-patient pairs involving 28 physicians (1.4% of mailings). Their demographic characteristics are shown in Table 2.

Characteristics of the patients who took part in the survey are shown in Table 3.

Table 2 Characteristics of Physicians Participating in Part 2 of the Study

	Physicians (n=28, if not indicated otherwise)
Age, years, mean (SD)	53.5 (8.3)
Sex, female, n (%) / male, n (%)	15 (53.6) / 13 (46.4)
Specialty, n (%)	
Psychiatry	18 (64.3)
Psychiatry and Geriatrics	1 (3.6)
Psychiatry and Neurology	8 (28.6)
Neurology	1 (3.6)
Clinical experience, years (SD)	24.8 (8.9)
Experience in psychiatry, years (SD) (n=27)	20.7 (8.2)
Current place of occupation, n (%)	
Clinic / Clinic and PIA	3 (10.7) / 4 (14.3)
Psychiatric Institutional Outpatient's Department (PIA) / PIA and Private Practice	3 (10.7) / 1 (3.6)
Private Practice	17 (60.7)
Experience treating patients with schizophrenia, years (SD)	21.8 (7.3)
Frequency of contact with patients with schizophrenia, n (%)	
Daily	12 (43)
Several times per week	13 (46)
Several times per month	3 (11)

Abbreviations: PIA, Psychiatric Institutional Outpatient's Department; SD, Standard deviation.

Table 3 Characteristics of Patients Participating in Part 2 of the Study

	Patients (n = 80, if not indicated otherwise)
Age, years, mean (SD) (n=79)	44.7 (12.9)
Sex, female, n (%) / male, n (%) (n=79)	31 (39.2) / 48 (60.8)
Age at diagnosis, years (SD) (n=77)	27.5 (8.9)
Duration of schizophrenia, years (SD) (n=77)	17.2 (10.6)
Medical treatment (n=77)	76 (98.7)
Current drug treatment, n (%) (n=75)	
Long-acting injectable antipsychotics	15 (20.0)
Oral antipsychotics	47 (62.7)
Both long-acting injectable and oral antipsychotics	13 (17.3)
Current treatment mode, n (%) (n=79)	
Outpatient	63 (79.8)
Inpatient	16 (20.3)
Current disease severity, n (%) (n=77)	
Mildly ill	11 (14.3)
Moderately ill	24 (31.2)
Markedly ill	32 (41.6)
Severely ill	10 (13.0)
Patient required help filling in patient sheet, n (%)	
Yes	59 (75.6)
No	19 (24.4)

Abbreviation: SD, Standard deviation.

Ratings in the Three Main Categories

Initially, physicians and patients were prompted to select the most important treatment goal category among the three categories effectiveness/symptom reduction, tolerability, and quality of life/functioning/participation. 45.1% of physicians identified quality of life/functioning/participation as the primary treatment goal category while 43.7% prioritized effectiveness. Similar trends were seen in patients' assessments with 48.3% emphasizing quality of life/functioning/participation and 40.0% prioritizing effectiveness. Tolerability was infrequently selected as the top priority (physicians: 11.3%, patients: 11.7%). There was substantial agreement between patients and physicians with 54.2% to 66.1% attributing the same level of importance to one of the three treatment goal categories. Figure 3 shows the distribution of ratings across these categories.

Effectiveness was rated as more important by physicians than by patients in 20.3% of the matched pairs whereas in 18.6% it was rated as more important by patients. Ratings of the category quality/functioning/participation were similar (more important for physician: 23.7%, more relevant for patient: 22.0%). However, in the case of tolerability, more patients assigned it higher relevance than physicians (18.6% vs 15.3%).

Psychiatrists as well as patients were also asked to select their most important treatment goal for the specifically listed treatment goals within each of the three categories. Physicians were asked to consider their answer for each included patient separately. While there was general agreement within the three goal categories, certain specific items revealed discrepancies.

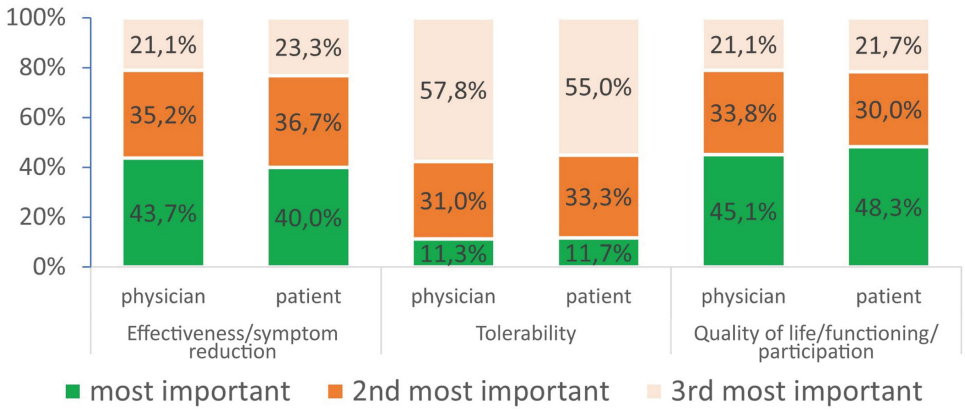

Figure 3 Frequency of rating a treatment goal category as most important second most important or third most important by patients and physicians. Duplicate ratings where more than one goal was rated as most important were not counted as valid answer.

Ratings in the Category Effectiveness/Symptom Reduction

An overview of psychiatrists' and patients' most important treatment goals within the category effectiveness/symptom reduction is given in Figure 4.

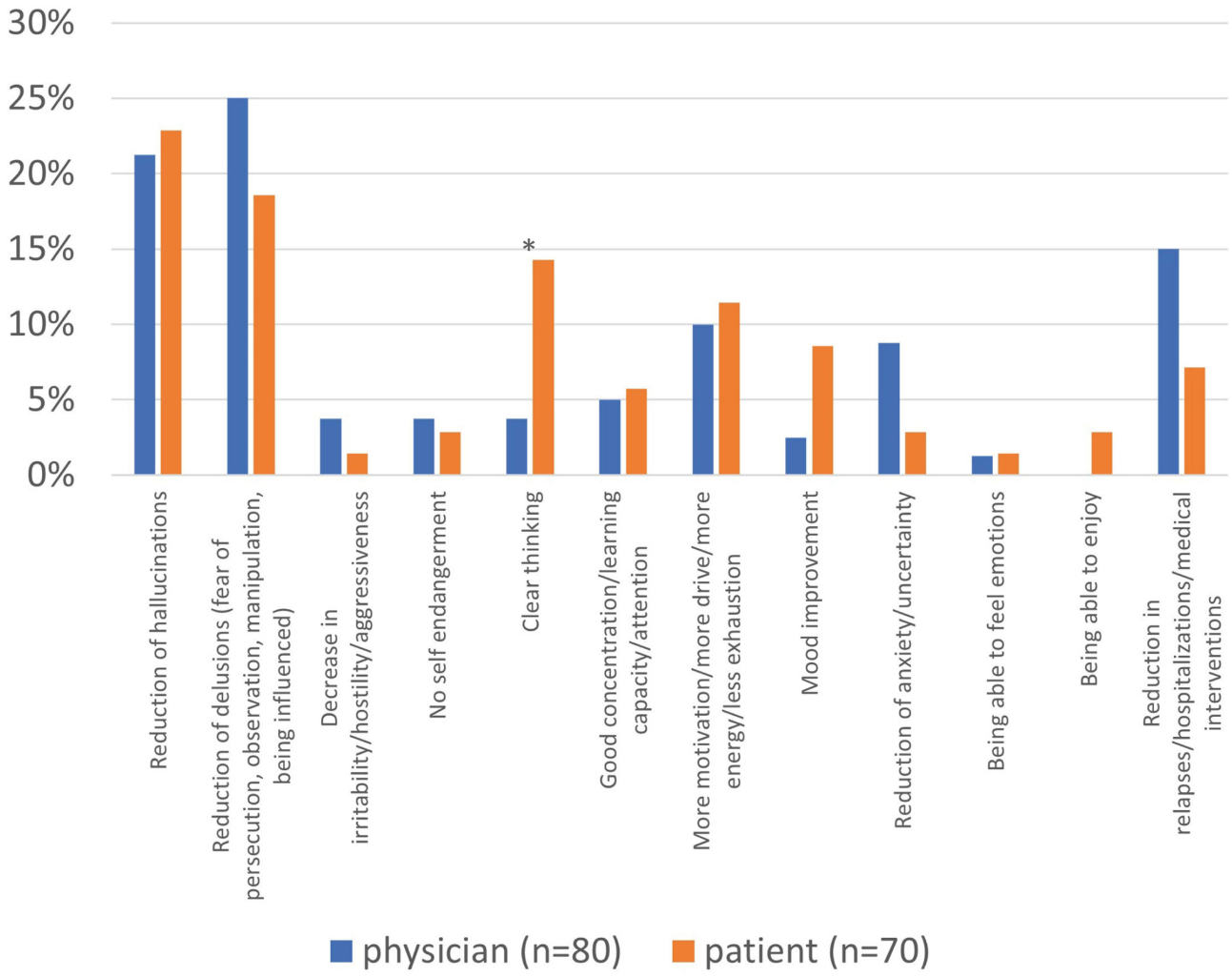

Figure 4 Frequency of ratings of treatment goals from the category effectiveness/symptom reduction as most important by patients and physicians. Duplicate ratings where more than one goal was rated as most important were not counted as valid answers. * $p < 0.05$.

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Both psychiatrists and patients mentioned the treatment goals "reduction of hallucinations" and "reduction of delusions" most often as the top treatment goal. However, physicians assessed "reduction of delusions" and "reduction in relapses/hospitalizations/medical interventions" more often (although not significantly) as the most important treatment goal within the category effectiveness than the patients did (p=0.11; p=0.17; McNemar's test). In contrast, patients rated "clear thinking" significantly more often as their priority than physicians did (p=0.02; McNemar's test).

Additionally, when asked for the most, second most or third most important goal within effectiveness, we saw that physicians tended to favour "reduction of anxiety/uncertainty" (p=0.02) whilst patients favoured "being able to enjoy" (p=0.03). Overall, "reduction of delusions" was marked as one of the three most important effectiveness goals most frequently both by patients (46.5%) and physicians (46.3%).

Additionally, participants were asked to give a rating for each of the possible treatment goals. Here, possible ratings were "most important", "also important", "less important" and "hardly important". The answers were transposed into a Likert scale with 1 = most important to 4 = hardly important.

The spider chart displays a comparison of the mean assessments of psychiatrists and patients (Figure 5). Rated relevance is lower towards the center and higher towards the periphery of the plot. Differences in answers between the matched pairs were compared using the signed rank test.

The treatment goals "clear thinking", "mood improvement" and "being able to enjoy" were valued significantly higher by patients than by physicians.

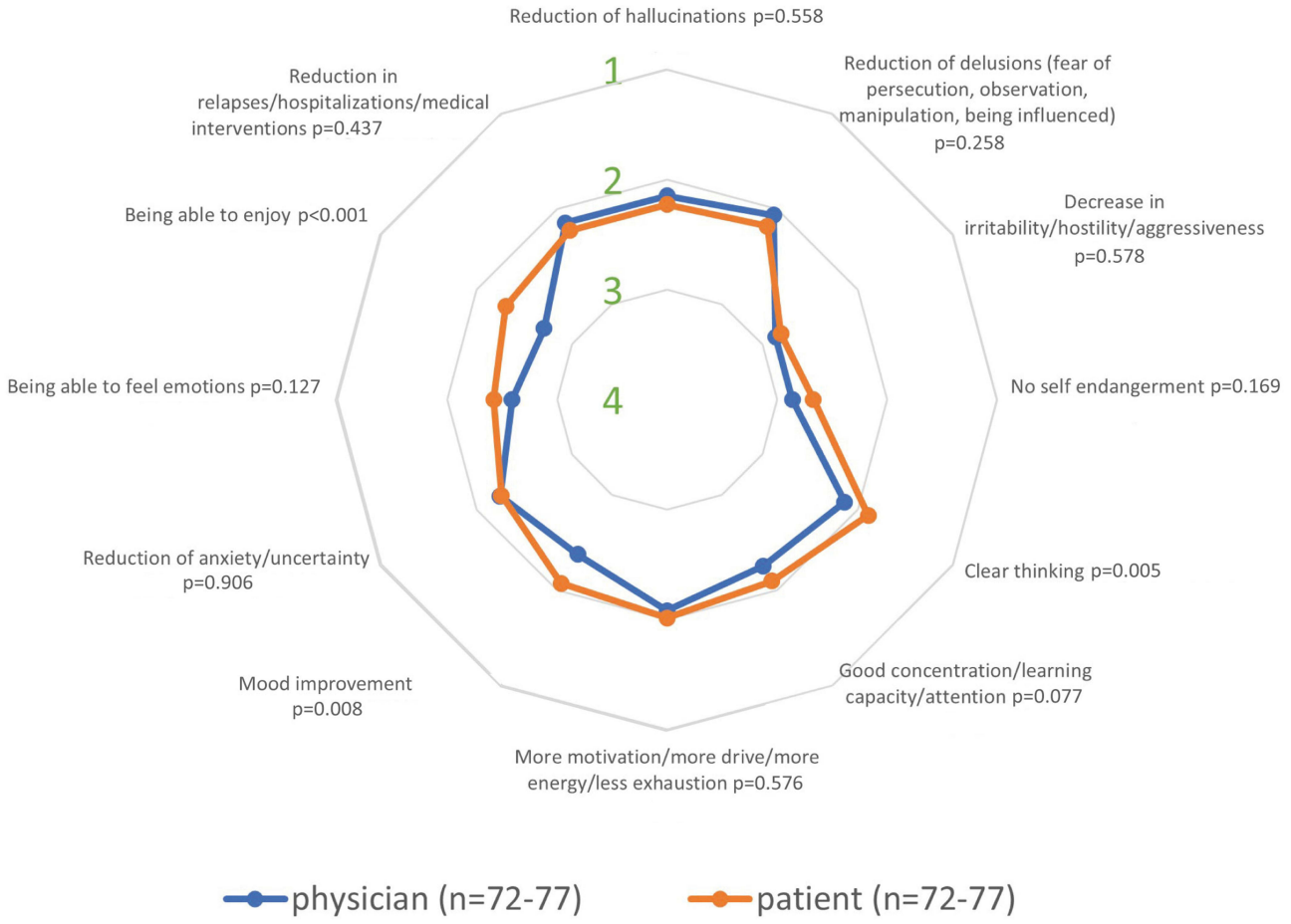

Figure 5 Rating of effectiveness goals by patients and physicians. 1=most important, 4=hardly important. P values are from a signed rank test.

Ratings in the Category Tolerability

When rating the most important treatment goal within the category tolerability, physicians showed a preference for "no or the least amount of fatigue/slowing down" ($p<0.01$) whereas patients emphasized "having no or the lowest level of metabolic disturbances" ($p=0.02$) and "no or the lowest level of cardiac dysfunction or other organ dysfunction" ($p<0.01$, Figure 6).

When participants were asked for their three top tolerability goals, similar findings were observed. Additionally, a difference showed for the goal "no or the least amount of weight gain" ($p=0.05$) and "not feeling subdued" ($p<0.001$) with a preference by the physicians.

The mean rating of each symptom as most important (=1) to hardly important (=4) is displayed in Figure 7. There was a higher importance rating of the tolerability goals "no or the least amount of fatigue/slowing down" and "not feeling subdued" by physicians whereas patients valued not having possible side effects like metabolic disturbances, cardiac or other organ dysfunction and "restlessness" higher.

Ratings in the Category Quality of Life/Functioning/Participation

The goal "establish and maintain close relationships" was assessed most frequently as the primary treatment goal in the category quality of life/functioning/participation both by physicians (24.1%) and by patients (29.0%). Differences in choice of the most important quality of life goal between psychiatrists and patients were not significant. Figure 8 shows the frequencies of prioritizations.

When asking for the most, second most or third most important treatment goal, a difference showed for the goal "disease control without medication" which was chosen more often by patients ($p=0.01$) and "maintenance of self–determination/autonomy" which was assessed relevant more often by physicians ($p<0.01$). In total, the "ability to establish and maintain close relationships" was assessed as one of the three most important quality of life goals most frequently by both patients (57.0%) and physicians (61.2%).

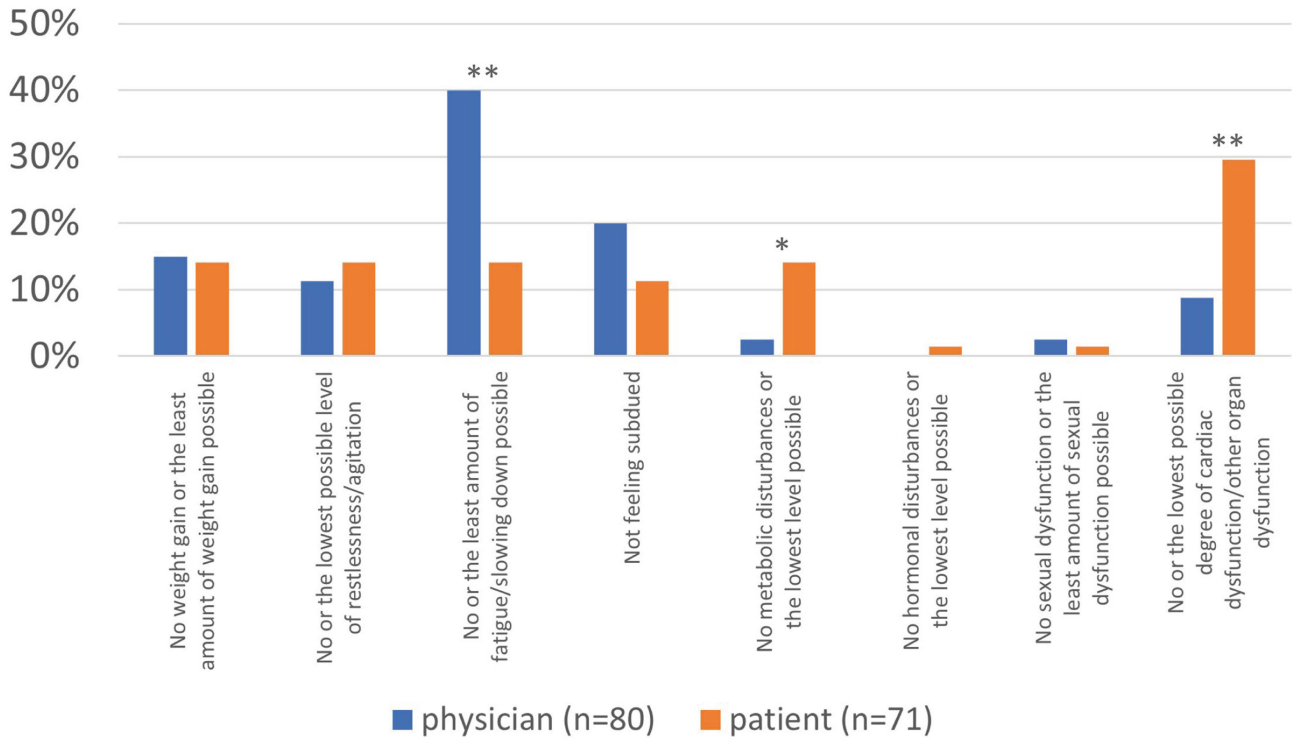

Figure 6 Frequency of ratings of treatment goals from the category tolerability as most important by patients and physicians. Duplicate ratings where more than one goal was rated as most important were not counted as valid answers. * $p < 0.05$; ** $p < 0.01$.

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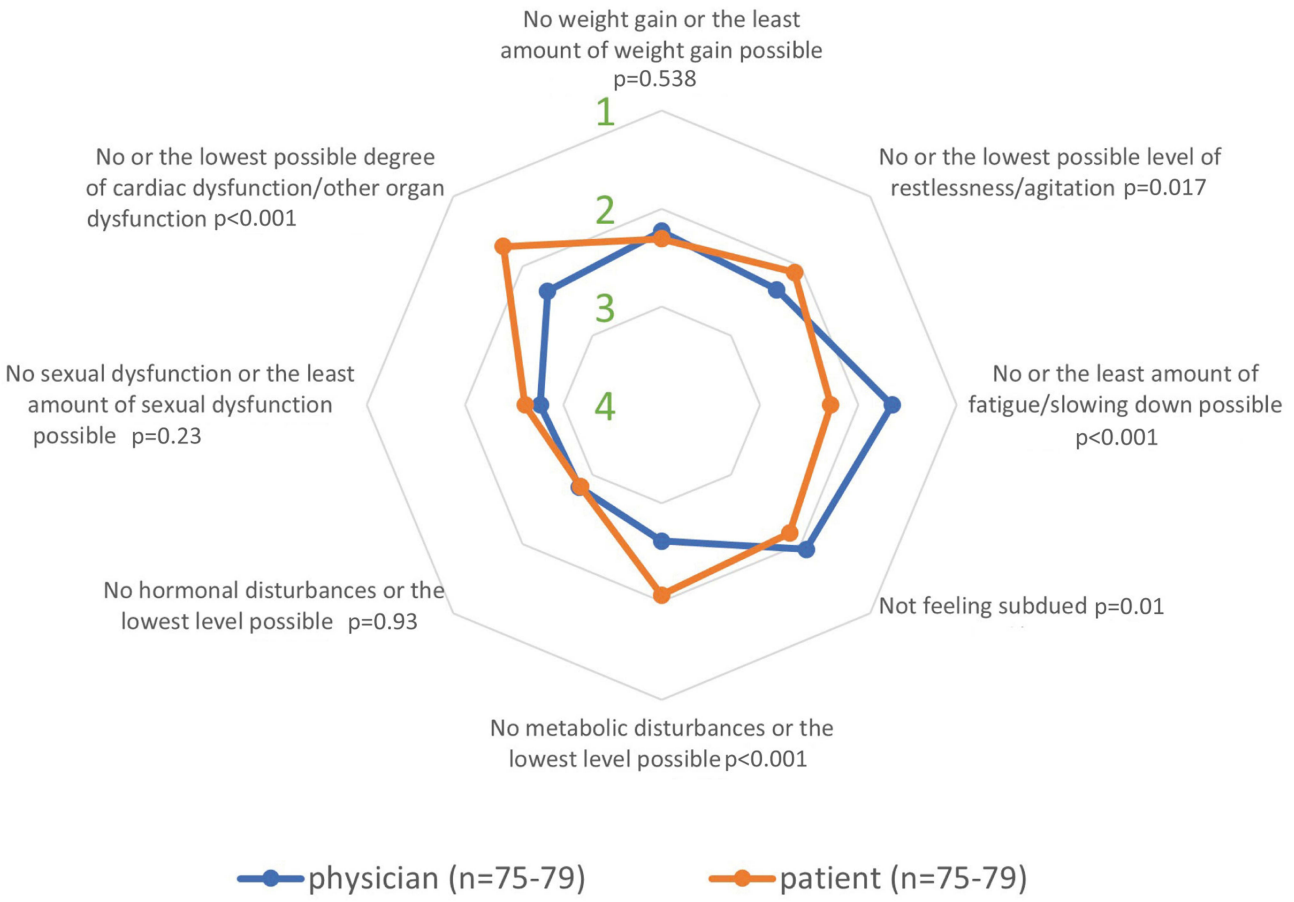

Figure 7 Rating of treatment goals of the category tolerability. 1=most important, 4=hardly important. P values are from a signed rank test.

Figure 9 shows a comparison of the mean ratings of psychiatrists and patients. Patients attributed significantly higher importance to treatment goals in relation to tasks of daily life and coping with illness ("regaining and maintaining abilities to manage activities of daily life", p=0.03; "self-care skills", p<0.01; "being able to pursue a hobby/leisure activities", p=0.01; "make sufficient use of health care services for concomitant somatic and psychiatric diseases", p<0.001 and "disease control without medication", p<0.001).

Subgroup Analysis of Inpatients Versus Outpatients

Sixteen patients were treated in hospital during the survey and 63 patients were out-patients. In general, similar answers compared to the total group were given by the two patient subgroups and their treating physicians. In the effectiveness category, the goal "clear thinking" was also more important for the patients, but a significant difference between psychiatrists and their patients was only seen in the outpatient group (p<0.01). The same applied for the goals "mood improvement" (p<0.01), "being able to feel emotions" (p=0.05) and "being able to enjoy" (p<0.01). "Reduction of anxiety/uncertainty" was more important to treating physicians of inpatients compared to their patients (p=0.03).

Regarding tolerability goals, a high value was assigned by physicians of inpatients as well as outpatients to "no or the least amount of fatigue/slowing down possible" (p<0.01 both). "Not feeling subdued" was of higher importance for psychiatrists of outpatients than for the patients themselves (p=0.04).

"No or the lowest possible degree of cardiac dysfunction/other organ dysfunction" was fundamental to both inpatients (p=0.04) and outpatients (p<0.01) whereas "no or the lowest possible level of restlessness/agitation" and "no metabolic disturbances or the lowest level possible" was more important to patients than to physicians in outpatients only (p=0.04 and p<0.01, respectively).

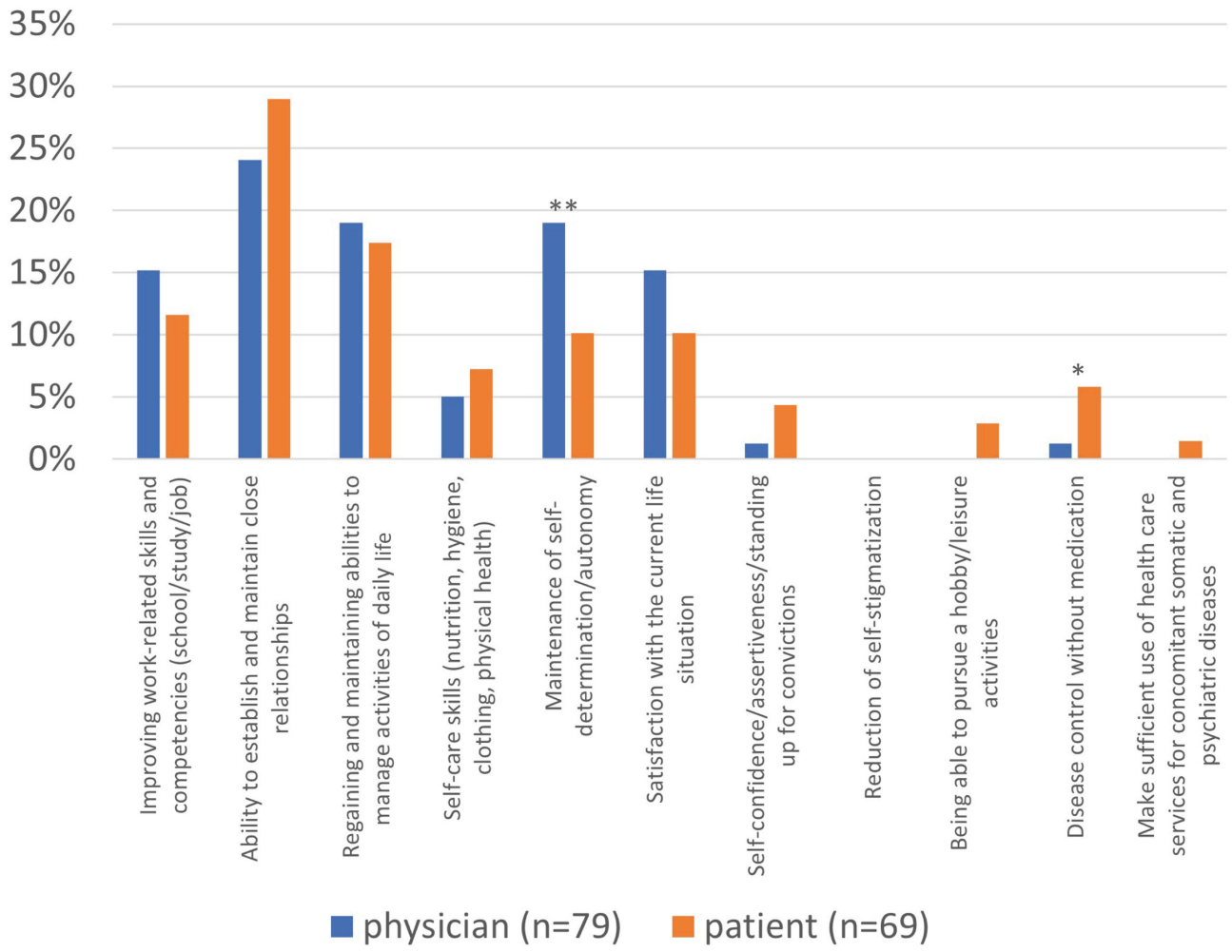

Figure 8 Frequency of ratings of treatment goals from the category quality of life/functioning/participation as most important by patients and physicians. Duplicate ratings where more than one goal was rated as most important were not counted as valid answers. * $p < 0.05$; ** $p < 0.01$.

For inpatients, "disease control without medication" was more important than for their treating physicians (p=0.02). For outpatients, the "ability to establish and maintain close relationships", "regaining being able to pursue a hobby/leisure activities" and "maintaining abilities to manage activities of daily life" (p=0.04 each) as well as "self-care skills (nutrition, hygiene, clothing, physical health"; p<0.01), "disease control without medication" and "making sufficient use of health care services for concomitant somatic and psychiatric diseases" (p<0.01 each) were significantly more relevant for patients compared to their treating psychiatrists.

Subgroup Analysis of Mildly and Moderately Ill Patients Versus at Least Markedly Ill Patients

Severity of schizophrenia had been classified as mildly or moderately ill by the attending physician in 35 patients and as markedly ill, severely ill or extreme severely ill in 42 individuals.

"Clear thinking", "good concentration/learning capacity/attention" and "mood improvement" were prioritized by lesser stricken patients compared to physicians (p=0.02, p=0.01 and p=0.03). "Being able to enjoy" was rated higher both by moderately ill patients (p=0.01) and markedly ill individuals (p=0.03).

"No or the lowest possible level of restlessness/agitation" (p=0.03), "no metabolic disturbances or the lowest level possible" and "no or the lowest possible degree of cardiac dysfunction/other organ dysfunction" (p<0.01 each) were important objectives for moderately ill patients.

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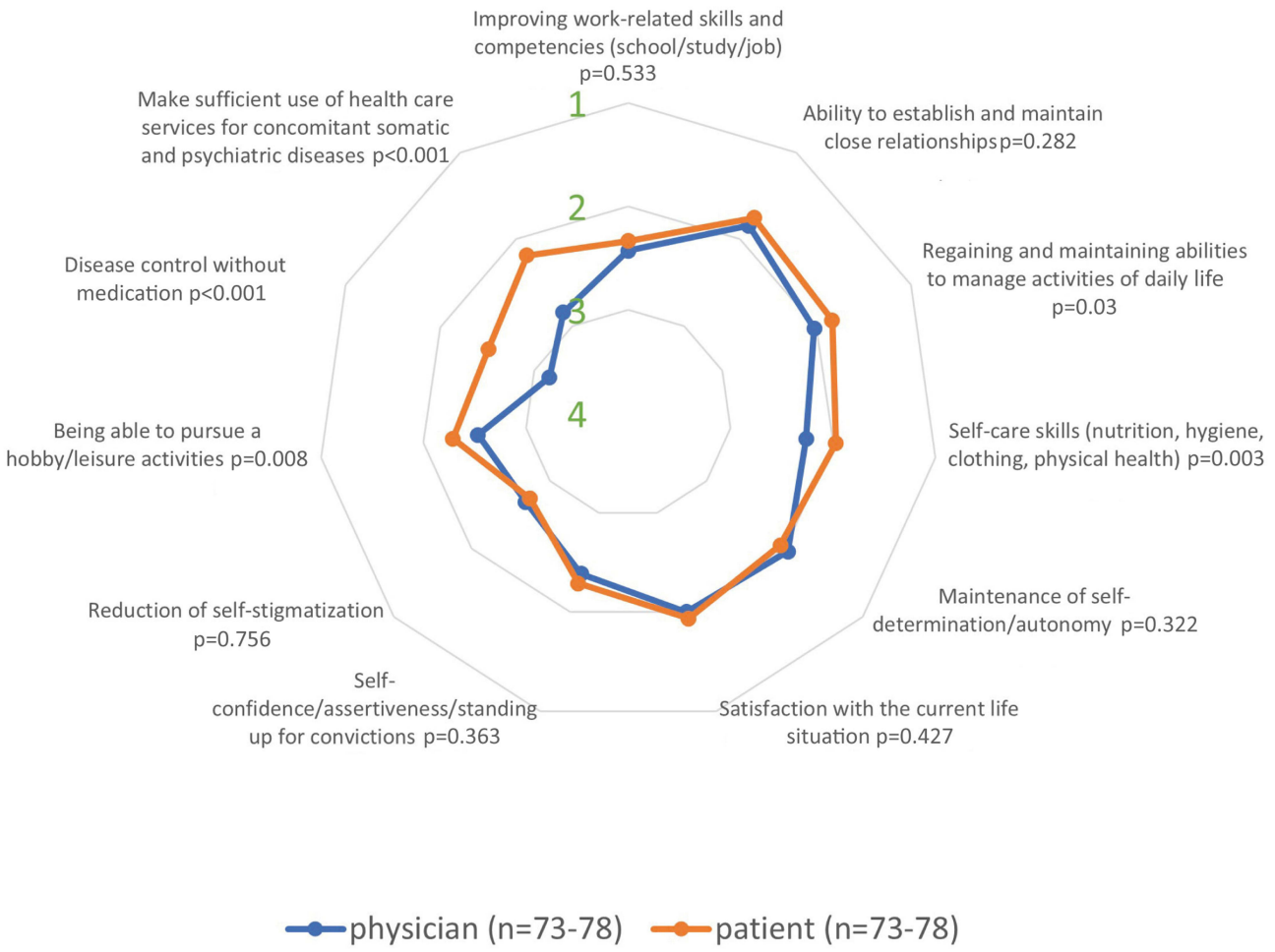

Figure 9 Rating of treatment goals of the category quality of life/functioning/participation. 1=most important, 4=hardly important. P values are from a signed rank test.

Severely ill patients feared "metabolic disturbances and cardiac dysfunction/other organ dysfunction" more than physicians anticipated ($p<0.01$ each) as well.

Physicians of both moderately ill and severely ill patients preferred "no or the least amount of fatigue/slowing down possible" ($p<0.01$ both) compared to their patients.

In moderate stages of the disease, the "ability to establish and maintain close relationships" ($p=0.04$), "maintaining abilities to manage activities of daily life" and "self-care skills" ($p<0.01$ each) as well as "being able to pursue a hobby/leisure activities" ($p=0.02$) was given higher value by patients than by physicians.

In both moderate and severe stages of the disease, "disease control without medication" and "making sufficient use of health care services for concomitant somatic and psychiatric diseases" was more important to patients compared to their treating physicians ($p<0.01$ each).

Discussion

Here, we evaluated treatment goals for schizophrenia, first in a three-step Delphi process that involved experts from academia and practice, and subsequently in a survey to evaluate the agreement on goals in matched physician-patient pairs.

In part 1 of our study, the three main categories (effectiveness/symptom reduction, tolerability, quality of life/functioning/participation) achieved high importance ratings and low standard deviations, indicating a consensus that all of these are important in the treatment of patients with schizophrenia. Furthermore, all individual goals also achieved

high ratings and low standard deviations, indicating consensus that all of these are important, except for "Disease control without medication". The latter was a controversial topic, with a range of responses from agreement (5 on the Likert scale) to full disagreement (1 on the Likert scale). This range of answers may be related to individual experiences of the physicians, or their assessment of whether this goal is realistic or feasible at all. The results were very similar for both hypothetical patients, indicating that the defined treatment goals may be broadly applicable in various stages of the disease.

In the second part of our study, 28 psychiatrists and 80 patients formed matched physician-patient pairs to assess the importance of possible treatment goals in the three categories effectiveness/symptom reduction, tolerability, and quality of life/functioning/participation. Patients were asked to evaluate the treatment goals for themselves, and their treating physicians were asked to evaluate the treatment goals for the specific patient of each matched-pair combination.

In general, agreement between psychiatrists and patients was high with around two-third of answers exactly equal for the three categories as being most important or being consistently ranked on the second or third place. Both patients and psychiatrists rated effectiveness and quality of life goals higher than tolerability goals.

The only other report with data on treatment goals in matched patient-physician pairs is, to our knowledge, a study by Ascher-Svanum et al, who reported on reasons for medication continuation or discontinuation.[7] Some of these reasons were related to met or unmet treatment goals. In their study, the percentage of agreement between patients and their clinicians on each of the reasons for discontinuing the medications prior to beginning the study was high, ranging from 67% to 99%. Correlations were also mostly high, ranging from 0.49 to 0.86, except for one item with an insufficient variation in responses ("New medical condition exacerbated by med", kappa=0.36). The percentage of agreement on each of the reasons for discontinuing the study medication ranged from 75% to 100% and kappa values ranged from 0.47 to 1.00, except for three items with insufficient variation. The percentage of agreement for continuing the study medication ranged from 58% to 88% and kappa values ranged from 0.53 to 0.70.[7]

Bridges et al[8] assessed treatment goals in 105 outpatients with schizophrenia and 160 psychiatrists in Germany by ranking and rating 20 treatment goals. They analyzed their results on a group level, not in matched pairs. A qualitative examination of treatment goal preferences uncovered that clinicians put greater emphasis on "reducing psychotic symptoms" compared to patients, while patients prioritized "improved activities of daily living." Collectively, while clinicians favored conventional "textbook" treatment goals, patients attributed higher importance to goals linked to everyday life, which is largely in line with our results.

In a study that was similar in design to ours, Fitzgerald and colleagues surveyed 124 psychiatrists, 555 patients and 135 caregivers for their view on treatment goals.[14] Again, analysis was done on a group level. Symptom reduction was identified as the most important treatment goal by patients (64%), psychiatrists (selecting for 63% of patients), and caregivers (selecting for 68% of patients). Also, all three stakeholder groups similarly rated the least important goals (less sexual problems and less weight gain). Interestingly, "Decrease in hospitalizations for relapse" was the second most important treatment goal for both psychiatrists (selected for 41% of patients) and caregivers (selected for 38% of patients), but was only the seventh most important goal for patients (21%).[14]

In our study, there was high agreement among effectiveness goals between patients and physicians. Interestingly, clear thinking, mood improvement and the ability to experience joy were significantly prioritized by the patients. Physicians tended to emphasize the reduction of delusions and decreasing the number of relapses and hospitalizations more. This is in line with prior studies on treatment goals[5,8,14] in which also reduction of symptoms and decrease in hospitalizations were prioritized treatment goals for clinicians compared to more difficult to capture goals like well-being and quality of life which were of greater importance to patients. It is possible that the goal to avoid relapses is even less important to patients after a first episode of psychosis, since they never experienced relapse.

In our analysis, differences between psychiatrists and patients were most pronounced in the tolerability category. Physicians rated fatigue/slowing down and feeling subdued as more important to avoid than the affected patients themselves did. Patients, however, showed a clearly higher concern of side effects like cardiac or other organ dysfunction, metabolic dysfunction and restlessness/agitation. This was seen in hospitalized patients as well as in outpatients and also applied for mildly ill to severely ill patients. Given this contrast, it can be assumed that medical therapy could benefit from more extensive information on possible side effects. Giving room for discussions of patients' concerns might lead to

a better adherence when unfounded fears could be taken from patients. The patient's view on tolerability goals may be strongly influenced by individual treatment experiences and risk profiles. Since the mean duration of schizophrenia was 17.2 years in our patient sample, we can assume that most patients had extensive experience with treatments for schizophrenia. Furthermore, the patient's view on tolerability goals may be influenced by age and gender, as young and physically healthy patients may be less likely to be afraid of somatic side effects, but eg the goal to avoid weight gain may also be a question of beauty ideality. On the whole, one could hypothesize that clinicians rate tolerability goals based on medical risk and manageability, while in patients, individual factors are more important.

Regarding quality of life, the greatest difference between patients and physicians was seen in the ability of making sufficient use of health care services for concomitant somatic and psychiatric diseases and disease control without medication. These two goals were hardly seen as important by physicians while they were essential to patients. Even in severely ill patients or in hospitalized patients these goals were given great relevance. Regarding disease control without medication, many physicians may assume that this is not a feasible goal, while patients tend to wish for a cure for their disease, rather than ongoing treatment.

Regaining and maintaining abilities to manage activities of daily life, self-care skills and the ability to pursue a hobby/leisure activities was more important to patients, too, albeit the difference was not that pronounced. However, this underlines previous findings indicating that physicians have a greater focus on textbook goals like reduction of specific symptoms.[5] The emphasis on quality of life has emerged as an important concept of patient-oriented medicine, although this was accepted with delay in the treatment of patients with schizophrenia.[4]

Identifying shared treatment goals between patients and physicians is crucial as it fosters patient-centered care rooted in collaborative decision-making. Consequently, common goals are central elements of long-term treatment adherence.[4]

Strengths and Limitations

Part 1 of our study was a well-defined, three-step process. Respondents were very experienced in the treatment of schizophrenia and can therefore be regarded as experts in the field. However, the surveyed psychiatrists are from a convenience sample that is likely not representative. Furthermore, we only got responses from 13.8% of the psychiatrists who received questionnaires. Our data is not powered for detecting statistical differences between the hypothetical patient vignettes or between goals. Still, a consensus was reached for 30 out of 31 treatment goals.

For part 2 of our study, sample size of physicians and patients was not formally calculated but grounded on feasibility. Our study was not powered for statistical testing, and all tests were exploratory in nature. This is especially true for the subgroup analyses that we conducted, considering that eg there were only 16 inpatients. Patient diagnoses were based on the judgement of the treating physician rather than a formalized diagnostic checklist. Therefore, the generalizability of our findings may be limited. However, physicians were selected from private practices, hospitals, and ambulatories all over Germany and patients with mild to severe disease were included.

Still, this is, to our knowledge, the first report of a study that individually matched physician-patient pairs specifically for their valuation of treatment goals.

Conclusions

We found that experts agree upon the importance of 30 treatment goals from three categories in the treatment of schizophrenia. Physicians and patients largely align on treatment goals. More emphasis may be placed on clarifying potential side effects of medical treatment. Physicians should be aware that patients' priorities could be more focused on improving quality of life and gaining autonomy rather than symptom management. By identifying shared treatment goals between patients and their physicians, adherence to therapy could see a notable enhancement.

Abbreviations

ICD-10, International Statistical Classification of Diseases and Related Health Problems, 10th Revision; IMDEC, International Medical and Dental Ethics Commission; PIA, Psychiatrische Institutsambulanz (Psychiatric Institutional Outpatient's Department); SD, Standard deviation.

Data Sharing Statement

The data that form the basis for this article are available from the authors upon reasonable request.

Ethics Approval and Informed Consent

The survey conducted within this study was presented to the International Medical and Dental Ethics Commission IMDEC, Freiburg, resulting in a positive vote. Participating physicians informed eligible patients verbally and in writing about the purpose and procedure as well as other details (including data protection) in connection with the interview. The patient was given a patient information leaflet containing all relevant points and, after an appropriate reflection period, gave written consent to participate. This study complies with the Declaration of Helsinki.

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Parts of the results, pertaining to part 1 of the study, have been presented as poster on the Kongress der Deutschen Gesellschaft für Psychiatrie und Psychotherapie, Psychosomatik und Nervenheilkunde (DGPPN), Berlin, 24.-27. November 2021.

Author Contributions

All authors made a significant contribution to the work reported, whether that is in the conception, study design, execution, acquisition of data, analysis and interpretation, or in all these areas; took part in drafting, revising or critically reviewing the article; gave final approval of the version to be published; have agreed on the journal to which the article has been submitted; and agree to be accountable for all aspects of the work.

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Disclosure

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