Evidence on the capacity of severe mental disorder patients to make well-founded decisions about their healthcare: a meta-review

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  decision making capacity; mental disorder; schizophrenia; bipolar disorder; literature review
Abstract

Background Determining the mental capacity of psychiatric patients for making decisions regarding treatment acceptance or refusal is crucial in clinical practice. This meta-review of review articles comprehensively examines the current evidence on the capacity of patients with a mental illness to make well-founded medical care decisions. Methods Systematic review of literature review articles following PRISMA recommendations. PubMed, Scopus and CINAHL were electronically searched up to 30 September 2019. Free text searches and medical subject headings in English were combined. Publications were selected as per inclusion and exclusion criteria. The AMSTAR 2 tool was used to assess the quality of reviews. Results Thirteen publications were reviewed. In one review, up to 67% of patients in a mixed psychiatric population had capacity to decide about admissions; 71% (median) had capacity for making decisions about treatments. In another, community-dwelling or clinically stable psychiatric outpatients were close to non-psychiatric subjects in decision capacity performance. In a third review, people with psychosis had moderately impaired risk-reward decision-making ability compared with healthy individuals ($g = -0.57$, 95% CI: -0.66 to -0.48; $I^2$ 45%), and were more likely to value rewards over losses ($k = 6$, $N = 516$, $g = 0.38$, 95% CI 0.05 to 0.70, $I^2$ 64%) and to base decisions on recent rather than past outcomes ($k = 6$, $N = 516$, $g = 0.30$, 95% CI: -0.04 to 0.65, $I^2$ 68%). In a fourth review, future care (crisis) planning led to a 40% reduction in the use of compulsory inpatient treatment over 15 to 18 months. In other reviews, patients with mental illness were able to provide valid preference measures and gave sufficiently consistent answers regarding their preferred treatments. Decision-making responded favourably to interventions. The publications complied satisfactorily with the AMSTAR 2 critical domains. Conclusions Whilst impairments in decision-making capacity may exist, most patients with a severe mental disorder are able to make rational decisions about their care. Best practice strategies should help mentally ill patients grow into voluntary and safe users of medications, enabling them to keep a sense of control over their lives and enhancing their health-related quality of life.

Background

In 1995, Appelbaum and Grisso stated that competence to consent to treatment relied on four legal
standards: the ability to communicate a choice; the ability to understand relevant information; the ability to appreciate the situation and its likely consequences; and the ability to manipulate information rationally (1). In healthcare, the capacity to make decisions regarding treatment is closely related to the autonomy, the exercise of self-governance, and the ability of an individual to take intentional actions (2). The capacity to consent to treatment is often used in the clinical assessment of the ability to engage in authentic autonomous decision-making, a fundamental element of a person’s dignity and rights (3).

Assessment of mental capacity has become a key component of daily clinical practice (4) (5). Mental health legislation and medical ethics increasingly require physicians to empower patients to make decisions, and also to respect the patient's wishes with regard to accepting or refusing therapy (4) (6). However, it has been reported that coercive treatment, involuntary hospitalisations and medications are currently overused (7); this has a direct negative impact on patients’ adherence to treatment and on their engagement and participation in shared decision-making with their healthcare professionals (8).

An increasing number of publications are assessing decision-making capacity in mental health. Systematic reviews bring together published studies in a single report in order to appraise the evidence; systematic reviews of reviews are the logical next step for comparing and contrasting the findings of individual reviews, so as to summarise the evidence and provide stakeholders with the information they need (9). This systematic review of review articles was designed as a comprehensive examination of the current state of knowledge in the field, with the aim of assessing the current evidence on the decision-making capacity of patients with various mental illness (especially schizophrenia, psychosis and bipolar disorder) with regard to their treatment and disease management. The review compares the conclusions of various comprehensive publications, discusses the strength of these conclusions, and identifies existing gaps in the evidence.

Methods
The review of the literature was conducted in accordance with the Preferred Reporting Items for Systematic Review and Meta-Analysis (PRISMA) guidelines (10). A series of steps, including the
definition of the search strategy, identification and selection of publications, data extraction and synthesis, and quality assessment was followed.

**Search strategy for identification and selection of publications**

The aim of the search strategy was to provide a comprehensive list of published literature reviews that met the inclusion criteria. Free text searches and medical subject headings were combined (Table 1) to identify literature reviews on decision making capacity in patients with mental disorders. Three electronic databases (PubMed, Scopus and the Cumulative Index to Nursing and Allied Health Literature [CINAHL]) were searched up to 30 September 2019. Lists of references in the key papers retrieved were further checked to identify other relevant articles.

Selection of publications was carried out as per inclusion and exclusion criteria (Table 2). Potentially relevant abstracts were assessed by two reviewers to identify all papers suitable for inclusion. Full text copies were requested. Reviews which were identified after mutual agreement were included and data were extracted. A third reviewer was involved in the process to resolve any disagreements on the selection of publications.

**Data extraction and quality assessment**

Data extraction was carried out by one researcher. A data extraction form that covered citation, country, population, interventions, comparators, outcomes, settings, review type, aims, literature review size, strengths and limitations and key findings of the review as stated by authors was used to extract data (Tables 3 and 4). The AMSTAR 2 (A MeaSurement Tool to Assess systematic Reviews) (11) assessment tool was used to assess the quality of reviews.

**Results**

A total of 714 publications were initially identified; 692 were either duplicated or deemed not relevant for the review based on the assessment of titles and abstracts; 22 full text publications were initially considered valid and retrieved for closer examination; 9 were excluded because they referred to diseases excluded from the review, 13 publications were finally included in the review (Figure 1). The number of studies included in each review varied between seven (12) (13) and 63 (14).

Observational and real-world experiences were summarised in 12 publications (12-23) including
cohort, case series and qualitative studies; one review (24) reported the findings from clinical trials. In eight reviews (13) (14) (16-18) (20) (22) (23) the studies compared two or more groups of patients. The general healthy population or groups of patients with a non-mental disorder were the comparators (Table 3). In four reviews (12) (15) (19) (21) no comparisons between groups were made. The number of patients with a mental disorder included in the reviews ranged between six (18) and 4,273 (16).

Four reviews focused on schizophrenia or schizoaffective disorders only (13) (17) (18) (22), four on psychosis (19) (12) (23) (24), one on bipolar disorder (16) and the other four on various mental disorders (14) (15) (20) (21). The MacArthur Competence Assessment Tool for Treatment (MacCAT-T) was the primary assessment instrument in eight reviews, while two reviews used the Iowa or Canada Gambling Tasks to assess capacity to make decisions. Nine of the reviews included in the present report were conducted by authors in European countries (12) (15) (17) (19-24), two were based in the United States (14) (18), one study was conducted in Australia (16), and another in several countries (13) (Table 4).

**Prevalence of decision-making capacity**

One systematic review of 37 empirical, quantitative studies of mental capacity in a mixed population of psychiatric patients reported that up to 67% of participants had the capacity to decide whether to be admitted to a psychiatric unit while a median of 71% had capacity for making treatment decisions (a median of 29%, interquartile range (IQR) 22-44, lacked capacity) (21). Another systematic review found that 26% (95% confidence interval (CI): 18 to 36) to 67% (95% CI: 35 to 88) of people with schizophrenia or other non-affective disorders were able to make medical decisions related or unrelated to the management of their condition (22). Overall, the definitions and measurement of capacity varied widely in the studies (21) (22).

**Decisional capacity in different clinical settings**

Capacity to consent to treatment or admission differed between patients in medical (non-psychiatric) settings and those in psychiatric settings. Lepping et al (2015) (20) reported that 55% of patients in psychiatric and 66% of patients in non-psychiatric settings had the capacity to make medical
decisions. However, most patients in psychiatric settings were inpatients. Appreciation of the problem and necessity for treatment were more frequently compromised in psychiatric patients, while non-psychiatric patients struggled primarily with reasoning. The authors found a significant variation between studies due to heterogeneity in designs and methods that reached 86% in psychiatric settings and 90% in non-psychiatric settings. Jeste et al (2006) (18) found a 48% to 79% overlap between people with schizophrenia and non-psychiatric patients on the MacArthur subscales, which indicated that most patients with schizophrenia had adequate decision-making capacity (18).

However, the proportion of inpatients and outpatients in the samples was highly heterogeneous. Community-dwelling or clinically stable outpatients were much closer to non-psychiatric subjects in terms of the capacity for decision-making, but psychotic inpatients had several characteristics which distinguished them from outpatients and temporarily limited their capacity. Greater severity of positive and negative symptoms, experiencing a stressful life event (e.g., hospitalisation), and often receiving higher doses of medication adversely impacted cognition among psychiatric inpatients (20).

The authors concluded that similar proportions of non-psychiatric and psychiatric outpatients either had or lacked capacity to consent to treatment or to hospital admission, and that impairment in the capacity to make decisions was not a distinguishing feature of schizophrenia patients (18) (20). Another meta-analysis of ten studies showed that compared to healthy controls, patients with schizophrenia or schizoaffective disorder were significantly more likely to have impaired decision-making capacity in terms of understanding, reasoning, appreciation and expression of a choice in clinical research and treatment, as measured by the MacArthur Competence Assessment Tool (MacCAT) instruments (13). However, some of the studies included in this meta-analysis found decisional capacity to be improved in patients with schizophrenia following intensive educational interventions. Furthermore, the standardised mean differences were more significant in older than in younger age subgroups, suggesting that, compared to their healthy counterparts, the impairment of decision-making capacity could be more obvious in older patients than in younger patients.

Another systematic review explored the degree of impairment in each dimension of decision-making capacity in schizophrenia patients compared to non-psychiatric controls, as assessed by the MacCAT
(17). The odds for a decreased understanding and a decreased appreciation were some five times higher in individuals with schizophrenia than in non-mentally ill controls, those for decreased reasoning almost four times higher, and those for a decreased aptitude to express a choice was over six times higher. The use of an enhanced informed consent form contributed to significant improvements in decision-making capacity compared to the use of standard forms. Decision-making capacity responded favourably to interventions, such as the simplification of the information, shared decision-making, and metacognitive training (19). The authors concluded that even if patients with schizophrenia have a significantly decreased decision-making capacity, they should be considered to be as competent as non-mentally ill controls unless very severe changes were identifiable during the clinical examination (17).

**Determining factors of decisional capacity**

In a systematic review and meta-analysis of factors that help or hinder treatment decision-making capacity in psychosis (23 studies, n= 1823), psychotic symptoms were found to have small, moderate and strong associations with appreciation, understanding and reasoning respectively (19). Better decisional capacity in psychiatric patients was associated with higher insight, better metacognitive ability, higher anxiety and lower perceived coercion. Psychosis, symptom severity, involuntary admission into hospital and refusal of treatment were the strongest risk factors for psychiatric patients to be judged as lacking capacity (21).

Likewise, Ruissen et al (2011) (12) reported a strong correlation between insight and capacity for making decisions in patients with different psychiatric illnesses. Psychotic patients with adequate insight were generally competent in making medical decisions, while non-psychotic patients with other diagnoses such as unipolar depression, post-traumatic stress disorder and personality disorders with adequate insight were not.

**Capacity of people with mental illness to make value-based and risk-reward decisions**

Since decision-making is the process of forming preferences for possible options, selecting and executing actions, and evaluating the outcome, the Iowa and the Cambridge Gambling Tasks (IGT and CGT) have been widely administered to measure decision-making capacity in mentally ill individuals,
even though they are not specifically designed for use in psychiatry (25). These tasks simulate real-life decision-making situations by manipulating the possibilities and magnitudes of potential rewards and punishments in a series of hypothetical scenarios presented to the patient (26).

A systematic review and meta-analysis explored the factors which may help or hinder the ability to make risk-reward decision making in a pooled sample of 4,264 individuals with psychosis, based on their performance on the IGT and the CGT. Compared with healthy individuals, people with psychosis had moderately impaired risk-reward decision-making ability (g = -0.57, 95% CI -0.66 to -0.48; I² 45%; moderate quality) (23). They were also more likely to value rewards over losses (k = 6, N = 516, g = 0.38, 95% CI: 0.05 to 0.70, I² 64%), and to base decisions on recent rather than past outcomes (k = 6, N =516, g = 0.30, 95% CI: -0.04 to 0.65, I² 68%). Analysis of the positive or negative influence of the type and dose of antipsychotics on decision-making capacity was inconclusive. The authors suggested that, although people with non-affective psychosis may make less effective decisions than healthy individuals in the IGT and CGT, their difficulties were moderate and comparable with those observed in other clinical groups.

Mukherjee and Kable (2014) (14) calculated that around 27% of patients with various mental disorders did not differ with respect to healthy individuals when deciding about losses and rewards on the IGT. Furthermore, individuals with mental illnesses had fewer deficits than individuals with frontal lobe lesions. The assessment of the severity of impairment across types of mental illness did not demonstrate any significant differences according to specific psychiatric diagnosis.

**Capacity of people with mental illness to choose treatments**

Eiring et al (2015) (15) investigated the relative value adults with a mental illness place on treatment outcomes, including the attributes of particular medications or medication classes and the consequences and health states associated with their use. It reported that patients were able to provide valid preference measures with the different methods applied, generally understood the tasks, and gave sufficiently consistent answers. Among patients with schizophrenia, positive, acute or psychotic symptoms appeared consistently among the least desirable outcomes. Negative symptoms,
such as reduced capacity for emotion, were found more desirable or less important than positive symptoms. Independence received high ratings and inpatient status low ratings. Overall, patients with schizophrenia tended to value disease states higher and side effects lower than other groups and perceived side effects more negatively than their therapists. Patients with bipolar disorder gave low values to mania and severe depression and reported weight gain to be important.

**Capacity of people with mental illness to engage in shared decision-making**

Fisher et al (2016) (16) found that patients with bipolar disorder preferred either sharing decision-making with their clinician (38.3% – 64.3%) or making the final decision alone (1.8% – 52.1%). Most patients wanted to be informed and to be asked to give their opinion on treatment options (75.7% – 93.4%) but preferred to rely on their clinician for professional advice (versus independent information-gathering, 61%) and for making the final treatment decision (64%). Patients’ desired level of involvement varied according to their current bipolar disorder symptoms and disability, and also according to individual changes over time. Although patient-clinician agreement on the final treatment decision was common (79%), agreement was more likely when the clinician elicited patient treatment preferences. Patients who were satisfied with their decision-making and with their level of involvement reported more positive outcomes, better medication adherence, and lower decisional uncertainty.

The review of randomised controlled clinical trials by Stovell et al (2016) (24) reported that shared decision-making for future care (crisis planning) for psychosis reduced the use of compulsory inpatient treatment over 15 to 18 months by approximately 40%. The benefits of shared decision-making included higher scores for treatment-related empowerment, sense of involvement in treatment, self-efficacy, and autonomy.

**Quality assessment**

Reviews presented well-framed research questions based on the evidence-based PICOS model (27) (Table 3) and were high quality according to the AMSTAR 2 assessment tool (Table 4) (11). AMSTAR 2 was developed to evaluate systematic reviews of randomised trials or non-randomised studies of healthcare interventions, or both. Publications included in this review complied satisfactorily the
AMSTAR 2 critical domains. No critical weaknesses were identified in the assessment. Therefore, the reviews provided an accurate and comprehensive summary of the results of studies of decision-making capacity in mental disorder patients.

Discussion
This systematic review brings together a set of high-quality reviews on the capacity of individuals with a severe mental illness to make decisions about their healthcare. The findings reveal that patients with psychotic disorders or other severe mental illnesses have the capacity to decide about their treatments and can make complex risk-reward decisions in usual clinical practice. Small deviations from optimal performance may arise due to deficits in the ability to fully represent the value of different choices and response options; similar results have been found in experimental research in patients with schizophrenia (28).

Most of the reviews appraised addressed the capacity to make decisions in people with severe mental disorders either requiring hospital admission or already hospitalised. This means that most studies included patients with severe symptoms or more severe mental disorders. Some required electroconvulsive therapy, which is most commonly used in patients with more severe symptoms that have failed to respond to other treatments (29). Even in these more severely ill psychiatric populations, between 60% and 70% had the capacity to make some treatment decisions (1).

Hospitalised patients usually have greater care needs, even when their psychiatric symptoms are controlled, exhibit significantly more severe negative, positive and manic symptoms, and have lower global functioning than outpatients (30). Therefore, decisional capacity can be expected to be higher amongst outpatients than among inpatients, and higher in everyday life than the rates reported in the studies included here.

This review shows that people with schizophrenia have the capacity to make difficult decisions related to hospitalisation, the type of treatment they prefer to receive, and their care plans. Patients with schizophrenia or bipolar disorder are able to describe prodromal symptoms of relapse and to suggest a treatment and the need for hospitalisation in advance; they can request or refuse medications and state their preferences for pre-emergency interventions, non-hospital alternatives and non-medical
personal care (31-33). It has been shown that advance directives are important to ensure the timely provision of medical treatments, thus minimising decisional impairments in the acute stages of psychosis (34).

Beyond acute episodes, the findings also support the notion that continued training and learning, simplification and enhancement of the information improve the capacity of patients with severe mental disorders for decision-making in everyday life (35). The results of various studies demonstrate that brief interventions aimed at recovering capacity for understanding can help schizophrenia patients to perform very much like healthy people in the four dimensions of decisional capacity (understanding, appreciation, reasoning and expression of a choice) (36). Regular information reinforcement, strengthening neurocognitive functioning and training are important to maintain long-term levels of competence and to maximise decision making capacities of patients (37) (40).

The MacCAT-T was the tool most frequently used to evaluate decision-making capacity in the studies reviewed. This instrument measures the individual capacity to consent to treatment with a semi-structured interview tailored to the patient’s specific disorder and treatment decision. Responses are rated by the clinician as 2, 1, or 0 (adequate, questionable, and inadequate), according to the specific situation or condition. There is no total score; each summary rating can be discussed separately and there are no cut-offs for individual summary scores (38). Therefore, the final decision depends entirely on clinical judgement, based on the practitioner’s knowledge of the patient and of the course of the disease.

Small sample size, heterogeneity, language and selection bias of participants were among the limitations frequently reported by the authors of the studies reviewed. However, since the publications included in the present report were systematic reviews and meta-analyses, the risk of bias was minimised.

Overall, this review provides solid support for the idea that the autonomy of severe psychiatric patients is preserved, and successfully challenges the idea that people with severe mental illnesses lack capacity and are unable to make their own choices (8). It contributes to the growing body of evidence suggesting that best practice strategies should help severe mentally ill patients to grow into
voluntary, safe users of medications and to recover a sense of control over their own lives, as preventing agitation and other acute symptoms and enhancing their health-related quality of life (39). It also reveals the gaps in the evidence regarding the capacity of people with severe mental illness to make appropriate clinical decisions in everyday life in the community. Authors across studies coincide in emphasising that most patients with a severe mental disorder are able to make rational decisions about their medical care and participate in decision-making regarding treatments despite the impairments in their decisional capacity. Impairment does not constitute incapacity to make decisions. Furthermore, advance directives are important to prevent crises and to minimise the impact of these negative events on patients’ health. Clinicians play the crucial role of judging the capacity of patients with severe mental disorder to decide about their treatments and healthcare. People with severe mental illness can benefit greatly from anticipation, prevention, gradual learning, enhanced information and enriched shared decision-making in order to strengthen their autonomous decision-making capacity, to increase their autonomy and to ultimately contribute to reducing the stigma of mental illness.

Conclusions
This systematic review of review articles provides a comprehensive examination of the current state of knowledge on the capacity of patients with mental illnesses to make decisions about their medical treatments. It provides clinicians and other healthcare practitioners a summary of the evidence on the topic. It shows that whilst impairments in decision-making capacity may exist, most patients with a severe mental disorder are able to make rational decisions about the care of their health. It denotes that best practice strategies should help mentally ill patients develop into autonomous and reliable users of medications, enabling them to keep a sense of control over their lives and enhancing their health-related quality of life.

Abbreviations
Declarations

Ethics approval and consent to participate: not applicable

Consent for publication: not applicable

Availability of data and materials

The datasets used and/or analysed during the current study are available from the corresponding author on reasonable request.

Competing interests:

The authors declare that they have no competing interests

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Authors' contributions:

SP developed the review and produced drafts of the manuscript; SP, AC, EV designed the study and analysed the data; all authors interpreted the data and were major contributors in writing the manuscript. All authors read and approved the final manuscript.

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References

1. Appelbaum P, Grisso T. The MacArthur Treatment Competence Study. I: Mental illness and competence to consent to treatment. Law Hum Behav. 1995;19(2):105–26.

2. Owen GS, Freyenhagen F, Richardson G, Hotopf M. Mental capacity and decisional autonomy: An interdisciplinary challenge. Inquiry. 2009;52(1):79–107.

3. Jeste D, Eglit G, PPalmer B, Martinis J, Blanck P, Saks E. Supported Decision Making in Serious Mental Illness. Psychiatry. 2018;81(1):28-40.
4. United Nations. Convention on the rights of persons with disabilities [Internet]. Report of the Convention. 2006. Available from: https://www.un.org/disabilities/documents/convention/convention_accessible_pdf.pdf

5. Harding R, Taşçioğlu E. Supported Decision-Making from Theory to Practice: Implementing the Right to Enjoy Legal Capacity. Societies. 2018;8(2):25.

6. Morrissey F. The United nations convention on the rights of persons with disabilities: A new approach to decision-making in mental health law. Eur J Health Law. 2012;19(5):423-40.

7. Mahomed F, Stein MA, Patel V. Involuntary mental health treatment in the era of the United Nations Convention on the Rights of Persons with Disabilities. PLOS Med. 2018;15(10):e1002679.

8. Danzer G, Rieger SM. Improving medication adherence for severely mentally ill adults by decreasing coercion and increasing cooperation. Bull Menninger Clin. 2016;80(1):30-48.

9. Smith V, Devane D, Begley C, Clarke M. Methodology in conducting a systematic review of systematic reviews of healthcare interventions. BMC Med Res Methodol [Internet]. 2011;11(1):15. Available from: http://www.biomedcentral.com/1471-2288/11/15

10. Moher D, Liberati A, Tetzlaff J, Altman D, Group. P. Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. PLoS Med [Internet]. 2009;6(7):e1000097. Available from: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2707599/pdf/pmed.1000097.pdf.

11. Shea BJ, Reeves BC, Wells G, Thuku M, Hamel C, Moran J, et al. AMSTAR 2: A critical appraisal tool for systematic reviews that include randomised or non-randomised studies of healthcare interventions, or both. BMJ. 2017;358:1-9.
12. Ruissen AM, Widdershoven GAM, Meynen G, Abma TA, van Balkom AJLM. A systematic review of the literature about competence and poor insight. Acta Psychiatr Scand. 2012;125(2):103-13.

13. Wang S Bin, Wang YY, Ungvari GS, Ng CH, Wu RR, Wang J, et al. The MacArthur Competence Assessment Tools for assessing decision-making capacity in schizophrenia: A meta-analysis. Schizophr Res [Internet]. 2017;183:56-63. Available from: http://dx.doi.org/10.1016/j.schres.2016.11.020

14. Mukherjee D, Kable JW. Value-based decision making in mental illness: A meta-analysis. Clin Psychol Sci. 2014;2(6):767-82.

15. Eiring Ø, Landmark BF, Aas E, Salkeld G, Nylenna M, Nytrøen K. What matters to patients? A systematic review of preferences for medication-associated outcomes in mental disorders. BMJ Open. 2015;5(4):1-13.

16. Fisher A, Manicavasagar V, Kiln F, Juraskova I. Communication and decision-making in mental health: A systematic review focusing on Bipolar disorder. Patient Educ Couns [Internet]. 2016;99(7):1106-20. Available from: http://dx.doi.org/10.1016/j.pec.2016.02.011

17. Hostiuc S, Rusu MC, Negoi I, Drima E. Testing decision-making competency of schizophrenia participants in clinical trials. A meta-analysis and meta-regression. BMC Psychiatry. 2018;18(1):2.

18. Jeste D V., Depp CA, Palmer BW. Magnitude of impairment in decisional capacity in people with schizophrenia compared to normal subjects: An overview. Schizophr Bull. 2006;32(1):121-8.

19. Larkin A, Hutton P. Systematic review and meta-analysis of factors that help or hinder treatment decision-making capacity in psychosis. Br J Psychiatry. 2017;211(4):205-15.
20. Lepping P, Stanly T, Turner J. Systematic review on the prevalence of lack of capacity in medical and psychiatric settings. Clin Med J R Coll Physicians London. 2015;15(4):337–43.

21. Okai D, Owen G, McGuire H, Singh S, Churchil R, Hotopf M. Mental capacity in psychiatric patients Systematic review. Br J Psychiatry. 2007;191:291–7.

22. Spencer BWJ, Shields G, Gergel T, Hotopf M, Owen GS. Diversity or disarray? A systematic review of decision-making capacity for treatment and research in schizophrenia and other non-affective psychoses. Psychol Med. 2017;47(11):1906–22.

23. Woodrow A, Sparks S, Bobrovskai V, Paterson C, Murphy P, Hutton P. Decision-making ability in psychosis: A systematic review and meta-analysis of the magnitude, specificity and correlates of impaired performance on the Iowa and Cambridge Gambling Tasks. Psychol Med. 2018;

24. Stovell D, Morrison AP, Panayiotou M, Hutton P. Shared treatment decision-making and empowerment-related outcomes in psychosis: Systematic review and meta-analysis. Br J Psychiatry. 2016;209(1):23–8.

25. Heerey E, Bell-Warren K, Gold J. Decision-Making Impairments in the Context of Intact Reward Sensitivity in Schizophrenia. Biol Psychiatry. 2008;64(1):62–9.

26. Nestor P, Choate V, Niznikiewicz M, Levitt J, Shenton M, McCarley R. Neuropsychology of Reward Learning and Negative Symptoms in Schizophrenia. Schizophr Res. 2014;159(0):506–8.

27. Cooke A, Smith D, Booth A. Beyond PICO. Qual Health Res [Internet]. 2012;22(10):1435–43. Available from: http://journals.sagepub.com/doi/10.1177/1049732312452938

28. Gold JM, Waltz JA, Prentice KJ, Morris SE, Heerey EA. Reward processing in schizophrenia: A deficit in the representation of value. Schizophr Bull.
29. Maguire S, Rea SM, Convery. Electroconvulsive therapy - What do patients think of their treatment? Ulster Med J. 2016;85(3):182-6.

30. Nakanishi M, Setoya Y, Kodaka M, Makino H, Nishimura A, Yamauchi K, et al. Symptom dimensions and needs of care among patients with schizophrenia in hospital and the community. Psychiatry Clin Neurosci. 2007;61(5):495-501.

31. Maitre E, Debien C, Nicaise P, Wyngaerden F, LeGadulec M, et al. Advanced directives in psychiatry: A review of the qualitative literature, a state-of-the-art and viewpoints. Encephale. 2013;39(4):244-51.

32. Wilder C, Elbogen E, Moser L, Swanson J, Swartz M. Medication Preferences and Adherence among Individuals with Severe Mental Illness Who Completed Psychiatric Advance Directives. Psychiatr Serv. 2010;61(4):380-5.

33. Gergel T, Owen GS. Fluctuating capacity and advance decision-making in Bipolar Affective Disorder - Self-binding directives and self-determination. Int J Law Psychiatry [Internet]. 2015;40:92-101. Available from: http://dx.doi.org/10.1016/j.ijlp.2015.04.004

34. Dornan J, Kennedy M, Garland J, Rutledge E, Kennedy HG. Functional mental capacity, treatment as usual and time: Magnitude of change in secure hospital patients with major mental illness Psychiatry. BMC Res Notes. 2015;8(1):1-9.

35. Owen G, David A, Hayward P, et al. Retrospective views of psychiatric in-patients regaining mental capacity. Br J Psychiatry. 2009;195(5):403-7.

36. Moser DJ, Reese RL, Hey CT, Schultz SK, Arndt S, Beglinger LJ, et al. Using a brief intervention to improve decisional capacity in schizophrenia research. Schizophr Bull. 2006;32(1):116-20.

37. Wang X, Yu X, Appelbaum S, Tang H, Yao G, Si T, et al. Longitudinal informed consent
competency in stable community patients with schizophrenia: A one-week training and one-year follow-up study. Schizophr Res. 2016;170(1):162–7.

38. Schaefer LA. MacArthur Competence Assessment Tools. Encycl Clin Neuropsychol. 2018;2051–7.

39. Jacob K. Recovery Model of Mental Illness: A Complementary Approach to Psychiatric Care. Indian J Psychol Med. 2015;37(2):117–9.

40. Sugawara N, Yasui-Furukori N, Sumiyoshi T. Competence to Consent and Its Relationship With Cognitive Function in Patients With Schizophrenia. Front Psychiatry. 2019;10:195. Published 2019 Apr 12. doi:10.3389/fpsyt.2019.00195

Tables

Table 1. Search terms

| 1. Identification of population of interest |
|--------------------------------------------|
| mental illness OR mental disorder OR psychiatric disorder OR schizophrenia OR bipolar disorder |

| 2. Identification of outcomes of interest |
|------------------------------------------|
| decision making capacity OR empowerment |

| 3. Identification of intervention |
|----------------------------------|
| pharmacological treatment/s OR medication/s OR consent |

Table 2. Selection criteria
Inclusion criteria:

Topics: decision-making capacity regarding pharmacological treatment/s and giving consent to treatment in mental health/illness, psychiatric disorders/schizophrenia/bipolar disorder

Type of study: review of the literature (any type) with a quantitative synthesis of results

Language of publication: English.

Setting: any setting (inpatient, outpatient, forensic)

Exclusion criteria

Animals, in-vitro, or other types of pre-clinical study

Studies on dementia, depression, Down syndrome, attention deficit hyperactivity disorders, autism spectrum disorder learning-, sleep-, eating-hoarding-, gambling- personality dissociative disorders

Clinical practice guidelines

Studies of: decision-making in presence of tumours of the central nervous system; cognition deficits occurring in the context of progressive chronic diseases (e.g., multiple sclerosis, cardiovascular, respiratory, infection diseases)

New-borns, infants, children or adolescent studies

Intellectual, developmental and learning disability studie:

Validation tool studies

Studies solely of the healthcare decision-making of professionals and carers of persons with mental disorder:

Studies on health- and social-care services provision plan

Studies on factors determining decision-making capacity regarding healthcare

Studies on interventions devoted to improving decision-capacity in mental disorder patients (decisional capacity assessed)

Table 3. Summary of the PICOS concepts in the reviewed publications

| Study | Country | PICOS | Population | N | Intervention | Comparator |
|-------|---------|-------|------------|---|--------------|------------|
| Eiring Ø et al 2015, (15) | Norway | Schizophrenia, depression, bipolar disorder, attention deficit hyperactive disorder | 1785 | Stated preferences by means of willingness to pay, conjoint analysis, discrete choice experiment | None |
| Fisher A et al 2016, (16) | Australia | Bipolar disorder | 4273 | Communication and decision-making | Healthy controls |
| Hostiuc S et al 2018, (17) | Romania | Schizophrenia | 684 | MacArthur Competence Assessment Tool - Clinical Research | Non-people (cont) |
| Jeste DV et al 2006, (18) | United States | Schizophrenia | Range: 6-80 | MacArthur Competence Assessment Tool - Treatment - Clinical Research | Non-people subject |
| Larkin A et al 2017, (19) | United Kingdom | Psychosis (non-affective psychotic disorder) | 1823 | Brief Psychiatric Rating Scale. Positive and negative syndrome | Non-people |
| Reference | Literature review domains | Aims/objectives | Literature review size, n | Key findings/conclusions (effect) |
|-----------|---------------------------|-----------------|--------------------------|----------------------------------|
| Lepping P et al 2015, (20) | United Kingdom | Psychiatric disorder patients | 2483 | Any validated tool to assess capacity for making decisions Non-mec |
| Mukherjee D et al 2014, (14) | United States | Mental illness patients | 1813 | Iowa Gambling Task Heall Indiv front |
| Okai D et al. 2007, (21) | United Kingdom | Psychiatric disorder patients | 851 | Vignettes, 15-item questionnaire, MacArthur Competence Assessment Tool-Treatment, semi-structured interview None |
| Ruissen AM et al 2011, (12) | Netherlands | Psychotic and non-psychotic disorder patients | 735 | MacArthur Competence Assessment Tool None |
| Spencer BWJ et al 2017, (22) | United Kingdom | Schizophrenia and non-affective disorders | Not reported | MacArthur Competence Assessment Tool-Treatment -Clinical Research None |
| Stovell D et al 2016, (24) | United Kingdom | Psychosis | 2238 | Shared decision-making interventions Heall |
| Wang SB et al 2017, (13) | Multicountry | Schizophrenia or schizoaffective disorder | 422 | MacArthur Competence Assessment Tool -Clinical Research -Treatment Heall |
| Woodrow A et al 2018, (23) | United Kingdom | Psychosis | 2276 | Iowa and Cambridge Gambling Tasks Heall |

Table 4. Summary of significant characteristics and findings of reviewed publications based on literature review domains
| Eiring Ø et al 2015, (15) | Systematic review | To investigate patients’ preferences for outcomes associated with psychoactive medications. | 16 |
|--------------------------|------------------|----------------------------------------------------------------------------------------------------------------------------------|----|
|                          |                  | Side effects and symptom outcomes outnumbered functioning and process outcomes. Severe disease and hospitalisation were reported to be least desirable. Patients with schizophrenia tended to value disease states higher and side effects as lower, compared to other stakeholder groups. In depression, the ability to cope with activities was found to be more important than a depressed mood. Patient preferences could not be consistently predicted from demographic or disease variables. |

| Fisher A et al 2016, (16) | Qualitative Systematic review | To systematically review studies of communication and decision-making in mental health-based samples including bipolar disorder patients. | 13 |
|--------------------------|-------------------------------|----------------------------------------------------------------------------------------------------------------------------------|----|
|                          |                               | Patients preferred: Shared decision making with their clinician: 38.3% to 64.3% Making the final decision alone: 1.8% to 52.1%. Passive role: 8.5% to 34.7%. Patients who perceived their therapeutic relationship as strong, positive and collaborative were more likely to indicate improved medication adherence, reduced suicidal ideation and greater satisfaction with psychiatric visit. |

| Hostiuc S et al 2018, (17) | Systematic review | To evaluate the degree of impairment in each dimension of decision-making capacity in schizophrenia patients compared to non-mentally-ill controls, as quantified by the MacArthur Competence Assessment Tool for Clinical Research instrument. | 13 |
|--------------------------|------------------|----------------------------------------------------------------------------------------------------------------------------------|----|
|                          |                  | Effect size: differences in means, schizophrenia vs non-mental illness patients Understanding: -4.43 (-5.76; -3.1, \(p < 0.001\)) Appreciation: -1.17 (-1.49, -0.84, \(p = 0.001\)) Reasoning: -1.29 (-1.79, -0.79, \(p < 0.001\)) Expressing a choice: -0.05 (-0.9, -0.01, \(p = 0.022\)) The odds for a decreased understanding in |

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Jeste DV et al 2006, (18)

Narrative review

To evaluate the magnitude of the difference between schizophrenia and non-psychiatric comparison subjects reported as well as the influence of sample characteristics on the effect sizes observed.

Schizophrenia vs non-psychiatric comparison subjects

Effect size:
- Understanding subscale (mean d = 0.88, SD 0.40, 7 studies),
- Appreciation subscale (mean d = 0.93, SD 0.34, 4 studies),
- Reasoning (mean d = 0.65, SD =0.34, 7 studies),
- Expression choice (mean d = 0.29, SD = 0.24, 4 studies).

Psychopathology (mean d = 2.06, SD = 1.03, 4 studies). Cognition (mean d = 1.01, SD 0.61, 6 studies).

Effect size comparing different MacArthur scales amongst inpatients with schizophrenia to non-psychiatric comparison subjects: range 0.45–1.54; median = 1.17

Effect size comparing different MacArthur scales amongst clinically stable outpatients with schizophrenia to non-psychiatric comparison subjects: range 0.0–0.84, median = 0.53

Larkin A et al 2017, (19)

Systematic review

To determine the direction, magnitude and reliability of the relationship between capacity in psychosis and a range of clinical, demographic and treatment-related factors

Association between total psychotic symptoms and capacity to understand information relevant treatment decisions:
- r=-0.45 (95% CI -0.5 to -0.34; =60%)
- Correlation between overall symptoms and ability to appreciate information for treatment decision:
- r=-0.23 (95% CI -0.1 to -0.32; =0%)
- Correlation between total symptoms and ability to reason in relation to treatment decision making:
- r=-0.31 (95% CI -0.4 to -0.12; =80%)

Lepping P et al 2015, (20)

Systematic review

To estimate the prevalence of incapacity to consent to treatment or admission in different medical and psychiatric settings, and compare the two

Inverse variation weighted prevalence for decision-making capacity for all the studies included was 41% (95% CI 35.6–46.2%). Heterogeneity was significant (Cochran Q 601; (df 69; p<0.001).
Psychiatric settings: the inverse variance weighted proportion of patients with incapacity was 45% (95% CI 39–51%). Heterogeneity was significant (Cochran Q 300; df 4; p < 0.001).

Medical settings: the inverse variance weighted proportion of patients with incapacity was 34% (95% CI 25–44%). Heterogeneity was significant (Cochran Q 267; df 2; p < 0.001), with inconsistency I² at 90% (95% CI 87–93%). Variation between studies due to heterogeneity was 90%.

Psychiatric and medical settings did not differ significantly from each other in terms of the proportion of incapacity (Cochran Q 0.66; df 1; p = 0.44).

| Study | Type of Review | Objective | Summary of Methods | Results |
|-------|----------------|-----------|---------------------|---------|
| Mukherjee D et al 2014, (14) | Systematic review | To assess value-based decision making in individuals diagnosed with mental illness. | 63, first meta-analysis (healthy populations and individuals with frontal lesions - and populations with mental illness) 40, second meta-analysis (as a function of type of mental illness) | Individual study effect sizes ranged from 0 to 1.55. Mean effect size was 0.58 (95% CI = −0.68 to −0.48, p < .001). Population with lesions performed significantly worse than the population with mental illness. Q (1) = 6.57, = .01, d = 0.52. Population with mental illness, mean performances in individual studies ranged from −6.72 to 10.20, average 0.45 (SE=0.88) |
| Okai D et al. 2007, (21) | Systematic review | To describe the clinical epidemiology of mental incapacity in patients with psychiatric disorders, including interrater reliability of assessments, frequency in the psychiatric population and associations of mental incapacity | 37 | Psychiatric in-patients lacking capacity reached 29% (median) (IQR 22–44). 67% had mental capacity to make decisions regarding admission to a psychiatric unit |
| Ruissen AM et al 2011, (12) | Systematic review | To review the scientific literature on the relationship between competence and insight in patients with psychotic disorders | 7 | Psychotic patients with poor insight are very likely to be incompetent |
In patients with psychiatric disorders, how competence and insight are connected in these patients, and whether there are differences in competence and insight among patients with different disorders.

| Study | Design | Aim | Results |
|-------|--------|-----|---------|
| Spencer BWJ et al 2017, (22) | Qualitative systematic review | To examine the presence or absence of decision-making capacity in schizophrenia and the associated socio-demographic/psychopathological factors. | 40 Decision-making capacity was present 48% of people (range: 26% - 67%). |
| Stovell D et al 2016, (24) | Systematic review | To examine the effects of shared decision-making on indices of treatment-related empowerment of people with psychosis | 11 Subjective empowerment N= 843, effect size (95% CI) g=0.30 (0.12, 0.48); 35% p=0.17 Risk of compulsory treatment N=872 RR=0.59 (0.35, 1.02) RD=70.10 (70.19, 0) NNT=10 (5,?) 61% P=0.08 Relationship with clinician N=1261 Relationship with clinician 60% P=0.2 and N= 1200 g=0.2; (0.07,0.35) 20% P=0.27 Clinician-rated decision-making abilities and knowledge N=520 g=0.27 (0.24, 0.35) 83% P=0.003 |
| Wang SB et al 2018,(13) | Systematic Review | To examine the decisional capacity measured by the MacArthur Competence Assessment Tools in schizophrenia. | 7 Decision-making capacity in schizophrenia patients compared to the healthy control Understanding (SMD = -0.81, 95% CI: -1.06 to -0.56, p< 0.001), Reasoning (SMD = -0.57, 95% CI: -0.80 to -0.34, p<0.001), Appreciation (SMD = -0.87, 95% CI: -1.20 to -0.53, p<0.001) Expression a choice (SMD = -0.24, 95% CI: -0.43 to -0.05, p = 0.01). |

Psychotic patients with adequate insight are generally competent non-psychotic patients are not. Most incompetent patients in this group have poor insight, but a substantial number of non-psychotic patients with adequate insight were incompetent. Non-psychotic patients with adequate insight can be incompetent.
Woodrow A et al 2018, (23)

Systematic review

To identify factors that may help or hinder decision-making ability in people with psychosis measured with Iowa or Cambridge Gambling Tasks

50

People with psychosis:
- had moderately impaired decision-making ability compared with non-clinical individuals: g = -0.57, 95% CI -0.66 to -0.48; I² 45% (moderate quality)
- were significantly more likely than healthy individuals to value rewards over losses: = 6, N = 516, g = 0. 95% CI 0.05 to 0.70, I² 64%.

Within the psychosis groups, decision-making performance had:
- a small-moderate inverse association with negative symptoms: k = 13, N = 648, r = -0.17, 95% CI -0.26 to -0.07, I² 32% (moderate quality),
- a small association with general symptoms: k = 5, N = 169, r = -0.13, 95% -0.25, -0.0. I² = 0% (low quality),
- no association with positive symptoms: k = 10, N = 512, r = -0.01, 95% CI -0.11 to 0.08 (moderate quality),
- no association between overall psychotic symptoms k=6, r= -0.10, 95% CI -0.21 to 0.02, I² = (very low quality),
- no association with current antipsychotic doses: N=171, r= -0.02, 95% CI -0.17 to 0.13, I² = 0% (low quality)

**AMSTAR 2 Score, interpretation:**
- High- Zero or one non-critical weakness: The systematic review provides an accurate and comprehensive summary of the available studies that address the question of interest;
- Moderate- More than one non-critical weakness*: The systematic review has more than one weakness: available studies that were included in the review;
- Low - One critical flaw with or without non-critical weaknesses: The systematic review has a critical flaw and may not provide an accurate and comprehensive summary of the available studies that address the question of interest;
- Critically low - More than one critical flaw with or without non-critical weaknesses: The systematic review has more than one critical flaw and should not be relied on to provide an accurate and comprehensive summary of the available studies.

CI: confidence interval; IQR: InterQuartile Range; OR: Odds Ratios; NNT: Number Needed to Treat; SD: Standard Deviation

Figures
Figure 1
PRISMA diagram

Supplementary Files
This is a list of supplementary files associated with this preprint. Click to download.
PRISMA 2009 checklist Manuscript Mental Disorders 23Jan2020.pdf