

Psychiatric Quarterly

Decision-making Capacity in Healthcare: Instruments Review and Reflections about its Assessment in the Elderly with Cognitive Impairment and Dementia --Manuscript Draft--

Manuscript Number:	PSAQ-D-20-00444	
Full Title:	Decision-making Capacity in Healthcare: Instruments Review and Reflections about its Assessment in the Elderly with Cognitive Impairment and Dementia	
Article Type:	Review Article	
Keywords:	Capacity assessment; Healthcare decision-making; Dementia; Mild cognitive impairment.	
Corresponding Author:	Ana Saraiva Amaral, Master Degree University of Coimbra Faculty of Psychology and Social Sciences: Universidade de Coimbra Faculdade de Psicologia e Ciências da Educação Coimbra, PORTUGAL	
Corresponding Author Secondary Information:		
Corresponding Author's Institution:	University of Coimbra Faculty of Psychology and Social Sciences: Universidade de Coimbra Faculdade de Psicologia e Ciências da Educação	
Corresponding Author's Secondary Institution:		
First Author:	Ana Saraiva Amaral, Master Degree	
First Author Secondary Information:		
Order of Authors:	Ana Saraiva Amaral, Master Degree	
	Rosa Marina Afonso, PhD	
	Mário Rodrigues Simões, PhD	
	Sandra Freitas, PhD	
Order of Authors Secondary Information:		
Funding Information:	Fundação para a Ciência e a Tecnologia (SFRH/BD/139344/2018)	Mrs. Ana Saraiva Amaral
Abstract:	<p>The prevalence of neurodegenerative diseases has been significantly increasing in the last decades, and it is expected to continue to grow. These health disorders can impair patients' decision-making capacity in healthcare. The capacity to make healthcare decisions is a fundamental pillar of informed consent, therefore, it should be carefully assessed. Clinicians' assessment, when not supported by a standardized tool, has revealed to be unreliable, so the recourse to an instrument of capacity assessment is crucial. The present paper aims to identify and summarize published instruments of healthcare decision-making capacity. To do so, a search of peer-reviewed articles in English, Portuguese and Spanish was conducted. A total of eighteen articles, detailing seventeen assessment instruments were selected. Instruments differ on format, structure, assessed abilities and psychometric properties. Likewise, instruments' targeted population also varies, with a few being specifically developed for patients with dementia. Although a high number of instruments were found, there is still no gold standard for healthcare decision-making capacity assessment. The lack of a gold standard highlights the need for more research in this field, as well as an effort to develop guidelines and normative data, in order to improve clinical practices.</p>	

Decision-making Capacity in Healthcare: Instruments Review and Reflections about its Assessment in the Elderly with Cognitive Impairment and Dementia

Ana Saraiva Amaral

Corresponding author.

PhD FCT grant (SFRH/BD/139344/2018), ORCID:0000-0003-1887-5027

Email: anapaula@fcsaude.ubi.pt

University of Coimbra, Center for Research in Neuropsychology and Cognitive and Behavioral Intervention (CINEICC), Faculty of Psychology and Educational Sciences (FPCEUC), Coimbra, Portugal;

Psychological Assessment and Psychometrics Laboratory (PsyAssessmentLab), Faculty of Psychology and Educational Sciences (FPCEUC), University of Coimbra, Coimbra, Portugal;

Health Sciences Research Center (CICS), University of Beira Interior (UBI), Covilhã, Portugal.

Rosa Marina Afonso

Email: rmafonso@ubi.pt

Department of Psychology and Education, University of Beira Interior (UBI), Covilhã, Portugal;

Center for Health Technology and Services Research (CINTESIS- ICBAS), Porto, Portugal.

Mário R. Simões

Email: simoesmr@fpce.uc.pt

University of Coimbra, Center for Research in Neuropsychology and Cognitive and Behavioral Intervention (CINEICC), Faculty of Psychology and Educational Sciences (FPCEUC), Coimbra, Portugal;

Psychological Assessment and Psychometrics Laboratory (PsyAssessmentLab), Faculty of Psychology and Educational Sciences (FPCEUC), University of Coimbra, Coimbra, Portugal;

University of Coimbra, Faculty of Psychology and Educational Sciences (FPCEUC), Coimbra, Portugal.

Sandra Freitas

Email: sandrafreitas0209@gmail.com

University of Coimbra, Center for Research in Neuropsychology and Cognitive and Behavioral Intervention (CINEICC), Faculty of Psychology and Educational Sciences (FPCEUC), Coimbra, Portugal;

Psychological Assessment and Psychometrics Laboratory (PsyAssessmentLab), Faculty of Psychology and Educational Sciences (FPCEUC), University of Coimbra, Coimbra, Portugal;
University of Coimbra, Faculty of Psychology and Educational Sciences (FPCEUC), Coimbra, Portugal.

Declarations

Funding: Ana Saraiva Amaral is a PhD student at University of Coimbra, supported with a national PhD grant from FCT (Fundação para a Ciência e a Tecnologia), the Portuguese public agency for science, technology and innovation.

Conflicts of interest/Competing interests: Not applicable.

Availability of data and material: Not applicable.

Code availability: Not applicable.

Ethics approval: Not applicable.

Consent: Not applicable.

Author contributions: All the authors participated actively in the study design, data collection and analysis and manuscript preparation.

Decision-making Capacity in Healthcare

**1 Decision-making Capacity in Healthcare: Instruments Review and Reflections about its Assessment in the
2 Elderly with Cognitive Impairment and Dementia****4 Abstract**

5 The prevalence of neurodegenerative diseases has been significantly increasing in the last decades, and it is
6 expected to continue to grow. These health disorders can impair patients' decision-making capacity in healthcare.
7 The capacity to make healthcare decisions is a fundamental pillar of informed consent, therefore, it should be
8 carefully assessed. Clinicians' assessment, when not supported by a standardized tool, has revealed to be
9 unreliable, so the recourse to an instrument of capacity assessment is crucial. The present paper aims to identify
10 and summarize published instruments of healthcare decision-making capacity. To do so, a search of peer-reviewed
11 articles in English, Portuguese and Spanish was conducted. A total of eighteen articles, detailing seventeen
12 assessment instruments were selected. Instruments differ on format, structure, assessed abilities and psychometric
13 properties. Likewise, instruments' targeted population also varies, with a few being specifically developed for
14 patients with dementia. Although a high number of instruments were found, there is still no gold standard for
15 healthcare decision-making capacity assessment. The lack of a gold standard highlights the need for more research
16 in this field, as well as an effort to develop guidelines and normative data, in order to improve clinical practices.

17 **Keywords:** Capacity assessment; Healthcare decision-making; Dementia; Mild cognitive impairment.

19 1. Introduction

20 To provide medical care, physicians need to obtain informed consent from their patients. This presumption relies
21 on the bioethical principle which stands for people's right to decide what happens to their own body. However,
22 in order to consider an informed consent as valid, three assumptions are required: disclosure of information,
23 voluntariness and capacity [1, 2]. Capacity to make healthcare decisions has been generally understood
24 accordingly to Grisso and Appelbaum's [3] model of four abilities. This model describes four functional abilities
25 implied in healthcare decision-making and is based on the legal standards of competence to consent [4]. The four
26 abilities are understanding, appreciation, reasoning and expressing a choice [5]. Understanding regards the ability
27 to understand the disclosed information about the disease, as well as the risks and benefits of each treatment
28 option. As for appreciation, it stands for the ability to apply the disclosed information to one's own problem.
29 Reasoning describes the process of weighing the risks and benefits of each treatment option, which allows the

30 patient to reach a decision. Finally, expressing a choice refers to the ability of communicating a clear and
31 consistent decision through speech, write, or other mean [5].

32 The assessment of capacity to consent to treatment is a routinely procedure in clinical practice [6]. Although,
33 some situations require a more thorough assessment, specially cases of mild cognitive impairment, dementia or
34 other health issues related to cognitive impairment.

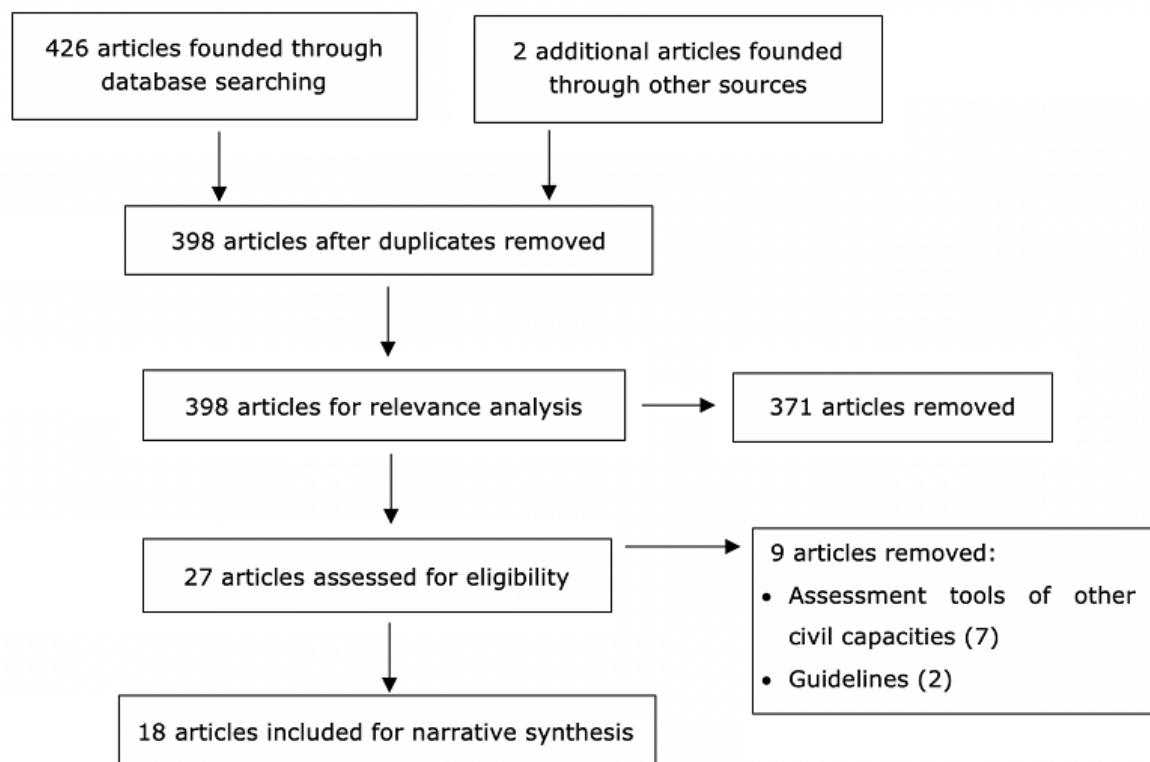
35 Frequently, capacity assessments are performed by clinicians in a non-structured way. However, clinical
36 assessment *per se* does not seem to be the most effective way to evaluate healthcare decision-making capacity,
37 since various studies have pointed out low interrater reliability between clinicians [4]. These limitations highlight
38 the need of a structured assessment of healthcare decision-making capacity, with recourse to a specific assessment
39 tool. Several instruments have been developed. This article aims to review the existing instruments, summarize
40 their content, administration procedures, psychometric properties, and reflect about their usefulness in people with
41 cognitive impairment and dementia.

42 43 **2. Method**

44 We conducted searches for English, Portuguese and Spanish papers, published between 1980 and 2018, describing
45 instruments of decision-making assessment in healthcare. The search terms used were “*capacity to consent to*
46 *treatment*”, “*competence to consent to treatment*”, “*healthcare decision-making*” and “*assessment tools*” or
47 “*assessment instruments*”. Searches were limited to peer-reviewed publications, and conducted in the following
48 databases: Web of Science (Web of Science Core Collection, Current Content Connect MEDLINE and Scielo),
49 EbscoHost (Psychology and Behavioral Sciences Collection, Cochrane database of Systematic Reviews,
50 Cochrane Clinical Answers, MEDLINE complete), Scopus, Wiley Online Library, Taylor & Francis Online,
51 Clinical Key, Proquest Psychology Journals, and PubMed.

52 Search results are presented in the flowchart below (fig.1). Articles describing assessment tools of healthcare
53 decision-making capacity were included. For this purpose, assessment tools should have a standardized scoring
54 procedure. Articles containing guidelines for clinical assessment of healthcare decision-making capacity were
55 excluded. Instruments of decision-making capacity in activities of daily living, advance directives, consent to
56 clinical research, and healthcare decision-making capacity in children were also excluded.

60 **Fig.1 Flowchart of literature review**



61

62

63 **3. Results**

64 Through online database research, 18 articles, describing 17 assessment instruments of healthcare decision-
 65 making capacity were included. Each instrument main features are presented in Table 1. More detailed
 66 descriptions can be found bellow.

67

68 Table 1: Assessment tools of Decision-Making Capacity in Healthcare

Instrument	Application Time	Format	Abilities included	Reliability	Cut-off scores	Pilot study participants
Two-Part Consent Form [7]	No information available.	Semi-structured interview.	Understanding.	Test-retest reliability, $r = .76$; Interrater reliability, $r = .96$; Agreement between judges, $.5 \geq k \leq .83$.	No information available.	Psychiatric patients referred to electroconvulsive treatment.
Direct Assessment of Decision-Making Capacity [8]	No information available.	Structured interview with clinical vignettes.	Understanding and Reasoning.	No information available.	Bellow the lower 99.5% confidence limit of control group mean.	Elderly inpatients with acute ill, without neurologic or psychiatric history.
Competency Interview Schedule [9]	No information available.	Structured interview.	Evidence a choice, Understanding, Appreciation and Evidence rational reasons for the choice.	Test-retest reliability, $r = .79$; Interrater reliability, ICC = .95; Inter-item correlation coefficients average = .64; Cronbach's alpha = .96.	No information available.	Psychiatric inpatients with recommendation to electroconvulsive treatment.
Understanding Treatment Disclosure [10]	25-30 minutes	Semi-structured interview with	Understanding.	Interrater reliability for individual items $k \geq .60$ for 90% of the comparisons, and	No information available.	Hospitalized groups: Schizophrenia or Schizo affective Disorder;

Decision-making Capacity in Healthcare

		clinical vignettes.		ICC \geq .84 for subtests scores; Test-retest reliability ranged from .50 to .80; Cronbach's alpha ranged between .55 - .85.		Major Depressive Disorder; and Ischemic Heart Disease. Community groups.
Perceptions of Disorder [10]	10-20 minutes	Semi-structured interview with clinical vignettes.	Appreciation.	Test-retest reliability between .48 and .90; Cronbach's alpha between .67 and .80.	No information available.	Hospitalized groups: Schizophrenia or Schizoaffective Disorder; Major Depressive Disorder; and Ischemic Heart Disease. Community groups.
Thinking Rational About Treatment [10]	25-30 minutes	Semi-structured interview with clinical vignettes.	Reasoning and Expressing a Choice.	Interrater reliability, for individual items $k \geq$.60 for 76% of the comparisons, and ICC \geq .88 for total scores; Test-retest reliability ranged from .66 to .68; Cronbach's alpha between .39 - .74.	No information available.	Hospitalized groups: Schizophrenia or Schizoaffective Disorder; Major Depressive Disorder; and Ischemic Heart Disease. Community groups.

Decision-making Capacity in Healthcare

<p>MacArthur Competence Assessment Tool for Treatment [11]</p>	<p>15-20 minutes</p>	<p>Semi-structured interview.</p>	<p>Understanding, Appreciation, Reasoning and Expressing a choice.</p>	<p>Interrater reliability, ICC = .99 for understanding, .87 for appreciation and .91 for reasoning.</p>	<p>No information available.</p>	<p>Hospitalized groups: Schizophrenia or Schizoaffective Disorder; Major Depressive Disorder; and Ischemic Heart Disease. Community groups.</p>
<p>Capacity to Consent to Treatment Instrument [12]</p>	<p>20-25 minutes</p>	<p>Structured interview with clinical vignettes.</p>	<p>Understanding, Appreciation, Reasoning, Expressing a choice and Making a reasonable choice.</p>	<p>Interrater reliability, $r = .83$ on interval scales and 96% agreement on categorical scales.</p>	<p>Two standard deviations below the control group mean for four abilities.</p>	<p>Elderly with probable Alzheimer's Disease and older control group.</p>
<p>SICIATRI [13]</p>	<p>20 minutes</p>	<p>Structured interview.</p>	<p>Awareness, Not waive the right to decide, Evidence a choice, Understanding, Wants to get better and Insight.</p>	<p>Interrater reliability, for individual items, $.14 \geq k \leq .82$.</p>	<p>No information available.</p>	<p>Psychiatric and medical inpatients.</p>
<p>Hopemont Capacity</p>	<p>30-60 minutes</p>	<p>Semi-structured interview with</p>	<p>Understanding, Appreciation and Reasoning.</p>	<p>Interrater reliability has consistently been of .90 or more.</p>	<p>No information available.</p>	<p>No information available. However, the instrument was designed to assess decision-</p>

Decision-making Capacity in Healthcare

Assessment Interview [14]		clinical vignettes.				making in nursing home residents.
Aid to Capacity Evaluation [15]	10-20 minutes	Semi-structured interview.	Understanding, Appreciation and Reasoning.	Interrater reliability, $k = .79$,	Overall impression of probably or definitely incapable according to ACE classification, associated with a score between 0-16 on Standardized Mini-Mental Examination.	Medical inpatients.
Vignette method described by Schmand [16]	No information available.	Structed interview, with clinical vignettes.	Understanding, Appreciation, Reasoning and Expressing a choice.	Internal consistency of .74; Agreement between the vignette method and clinical judgment, $k = .36$.	Fifth centile of control group.	Community dwelling elderly with dementia syndromes (minimal, mild and moderate) and cognitively intact elderly.
Decision Assessment Measure [17]	No information available.	Semi-structured interview	Understanding and Retaining information, and Expressing a choice.	Interrater reliability, $k = .87$.	No information available.	Groups with mental illness: Dementia, learning disability and schizophrenia or schizoaffective disorder. Control group.

Decision-making Capacity in Healthcare

<p>Capacity Assessment Tool [18]</p>	<p>A few minutes, not specified.</p>	<p>Semi-structured interview.</p>	<p>Communication, Understanding choices, Comprehension of risks and benefits, Insight, Decision process and Judgment</p>	<p>Agreement between CAT and Psychiatrist's evaluation, $.77 \geq k \leq 1$.</p>	<p>No information available.</p>	<p>Elderly hospitalized in a Geriatric Unit or followed at the Unit's consultation service.</p>
<p>Assessment of Consent Capacity – Treatment [19]</p>	<p>45 minutes</p>	<p>Structured interview with clinical vignettes.</p>	<p>Understanding, Appreciation, Reasoning and Expressing a Choice.</p>	<p>Interrater agreement across the vignettes between 97% - 98%; Cronbach's alpha between .82 and .88.</p>	<p>No information available.</p>	<p>Groups with mild and moderate mental retardation. Control group.</p>
<p>Vignette Method by Vellinga [20]</p>	<p>No information available.</p>	<p>Structured interview with clinical vignettes.</p>	<p>Understanding, Appreciation, Reasoning and Expressing a Choice.</p>	<p>Interrater reliability, $k = .64$.</p>	<p>Fifth centile of the control group.</p>	<p>Elderly with dementia (58,8%) and without (37,5%).</p>
<p>Assessment of Capacity to Consent to Treatment [21]</p>	<p>No information available.</p>	<p>Semi-structured interview with clinical vignettes.</p>	<p>Understanding, Appreciation, Reasoning and Expressing a Choice.</p>	<p>Interrater reliability, $r = .90$; Cronbach's alpha of .96.</p>	<p>2 standard deviations below the control group mean for understanding,</p>	<p>Elderly with dementia or schizophrenia. Control groups.</p>

15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60
61
62
63
64
65

Decision-making Capacity in Healthcare

					appreciation	and	
					reasoning.		

69

70 *3.1 Two-Part Consent Form*

1
2 71 The Two-Part Consent Form was developed to assess capacity to consent electroconvulsive treatment in
3
4 72 psychiatric patients [7]. The first part presents information about electroconvulsive therapy and it is followed by
5
6 73 a questionnaire of fifteen items, which evaluate patients' understanding of the disclosed information.
7
8 74 Understanding is measured by recall tasks, language understanding and reasoning. Patients' answers are scored
9
10 75 between 0 and 2, with higher scores representing higher understanding. A total score can be obtained by summing
11
12 76 all individual scores. The pilot study was performed with a sample of psychiatric patients, to whom
13
14 77 electroconvulsive therapy had been recommended. The study included a total of fifty seven patients, forty four
15
16 78 who had consent electroconvulsive treatment, and thirteen who had refused it [7].
17

18 79
19
20 80 *3.2 Direct Assessment of Decision-Making Capacity*

21
22 81 Fitten and Waite [8] proposed an assessment tool to evaluate treatment decision-making capacity in elderly
23
24 82 patients with acute ill. This instrument presents three clinical vignettes of increased complexity, followed by a
25
26 83 structured interview. After each vignette's presentation participants are asked to make a decision about treatment.
27
28 84 The vignettes describe problems of insomnia, pleural effusion and resuscitation in chronic illness. The Direct
29
30 85 Assessment of Decision-Making Capacity assesses the ability to understand the medical problem, proposed
31
32 86 treatments, its risks and benefits, and reasoning. Patients' answers are scored as complete (2 points), partial (1
33
34 87 point) or no understanding of the question (0 points). Validation studies included twenty five inpatients over 60
35
36 88 years old, without history of neurologic or psychiatric problems and a control group with twenty five community-
37
38 89 dwelling volunteers. Inpatient participants showed significantly lower scores on the clinical vignettes [8].
39

40 90
41
42 91 *3.3 Competency Interview Schedule*

43
44 92 Developed by Bean and collaborators [9], Competency Interview Schedule (CIS) aims to evaluate psychiatric
45
46 93 patients capacity to consent to electroconvulsive therapy. CIS is a questionnaire of fifteen questions that assesses
47
48 94 the ability to evidence a choice, to understand information related to treatment, to appreciate the nature of the
49
50 95 situation and its consequences, and to evidence a rational reason for the choice made. Patients' answers are rated
51
52 96 in a Likert scale of seven points, where lower scores correspond to more adequate answers. Psychometric studies
53
54 97 were performed with a sample of ninety six subjects admitted to a psychiatric hospital, who had been diagnosed
55
56 98 with schizophrenia, schizoaffective, depression, mania, or other disorders [9].
57
58
59 99

100 3.4 MacArthur Treatment Competence Study Instruments

1
2 101 MacArthur Treatment Competence Study aimed to develop measures of competence to consent to treatment.
3
4 102 During its course, three instruments were developed Understanding Treatment Disclosure, Perceptions of
5
6 103 Disorder and Thinking Rational About Treatment. These instruments were designed based on the legal standards
7
8 104 of capacity to consent to treatment: understanding, appreciation, reasoning and expressing a choice. The studies
9
10 105 conducted included three clinical samples, named as hospitalized groups, and three community samples (non-
11
12 106 hospitalized groups), with equivalent age, gender, ethnicity and socioeconomic status. The hospitalized groups
13
14 107 included patients with schizophrenia or schizoaffective disorder ($n=75$), major depressive disorder ($n=92$) and
15
16 108 ischemic heart disease ($n=82$) [22].
17
18 109 Understanding Treatment Disclosure (UTD) is a structured interview that assesses the ability to understand
19
20 110 information about treatment. It starts with the presentation of a standardized vignette disclosing information for
21
22 111 informed consent. Three clinical vignettes were developed for this instrument, related to the disorders of the
23
24 112 hospitalized groups. In the assessment with UTD, each vignette is first presented in an “uninterrupted disclosure”
25
26 113 format, without any questioning occurring. After the uninterrupted disclosure, ten standardized questions are
27
28 114 made. Then, the vignette is presented again, in an “element disclosure” format, with each paragraph presented at
29
30 115 a time. Each paragraph is followed by standardized questioning, which contain questions demanding information
31
32 116 recall and recognition tasks. Each answer is classified in a three-point Likert scale (0-2). There are no instructions
33
34 117 for a total score, but for three sub-ranking-scales scores, which represent the scores obtained after the
35
36 118 uninterrupted disclosure and element disclosure (information recall and recognition questions) [10].
37
38 119 Perceptions of Disorder (POD) assesses the ability to appreciate the situation and its consequences to one’s own
39
40 120 situation. Considering the three clinical groups, three forms of Perceptions of Disorder were developed. Each
41
42 121 form is composed by three parts, but only two will be discussed, since research results of the third part have not
43
44 122 been found during the research. The first part is Non-Acknowledgment of Disorder and the second Non-
45
46 123 Acknowledgment of Treatment Potential. Each part presents a piece of information about the disorder and the
47
48 124 treatment, respectively. After each part being presented, patients are asked to rate in a six-point scale how much
49
50 125 they believe that the information applies to their own situation. Then, patients are asked to explain their reasons,
51
52 126 which are rated between 0 and 2, with lower scores indicating greater non-acknowledgment [10, 23].
53
54 127 Thinking Rational About Treatment (TRAT) was also developed as a research instrument in MacArthur Treatment
55
56 128 Competence Study. It measures the ability to reason or rational manipulate information, through the assessment
57
58 129 of cognitive functions involved in decision-making processes. This instrument is composed by two parts: 1)
59
60
61
62
63
64
65

130 vignette presentation, followed by a series of questions that measure five cognitive functions; and 2) three tasks,
131 unrelated to the vignette, which assess three more cognitive functions. Therefore, TRAT has a total of eight
132 questions, that are scored between 0 and 2. A total TRAT score may be obtained by summing the scores of the
133 eight questions. The authors also developed a TRAT-2 score, that includes only six of the eight tasks. This
134 instrument also includes one item to assess the ability to express a choice, which can be rated between 0 and 2
135 [10, 22].

136

137 *3.5 MacArthur Competence Assessment Tool for Treatment*

138 MacArthur Competence Assessment Tool for Treatment (MacCAT-T) was based on Treatment Competence
139 Study. It merges the three previous instruments into a structured interview, which allows the assessment of
140 understanding, appreciation, reasoning and expressing a choice. The MacCAT-T does not include clinical
141 vignettes, so decision-making capacity is assessed in real-life context. The scoring criteria allows to classify
142 patients' answers between 0 and 2, with higher scores representing more adequate responses. Based on the
143 theoretical assumption that there are no universal levels of abilities which can distinct between competence and
144 incompetence, no cut-off scores are proposed. In the same way, as an impairment in a specific ability could
145 compromise decision-making capacity, there are no instructions for calculating a total MacCAT-T score. The
146 MacCAT-T study was developed with a clinical sample of hospitalized patients with schizophrenia ($n=40$) and a
147 control group from community ($n=40$) [11].

148

149 *3.6 Capacity to Consent to Treatment Instrument*

150 Capacity to Consent to Treatment Instrument (CCTI) is a structured interview developed to assess capacity to
151 consent to treatment, especially in people with dementia. It contains two clinical vignettes, presenting a neoplasm
152 and a cardiac problem, where symptoms and two possible treatments are described. After each vignette being
153 presented (orally and in writing), patients are asked fourteen standardized questions. CCTI assesses the ability to
154 express a treatment choice, make a reasonable choice, appreciate emotional and cognitive consequences of
155 treatment, reasoning and understanding the medical condition and treatment choices. Patients' answers are scored
156 according to two scoring systems: Quantitative and Qualitative scoring. The first scoring system rates patients'
157 answers between 0 and 2 points. In the pilot study, scores of each ability were considered separately. A cut-off
158 score of 2 standard deviations below the control group mean for the abilities *express a treatment choice*,
159 *appreciate consequences, reasoning and understanding* was considered as an indicative of lack of competency.

160 The Qualitative scoring system identifies sixteen types of errors, due to language dysfunction, executive
161 dysfunction, affective dysfunction or compensatory responses [12]. A recent study proposes an experimental total
162 score of CCTI. Age-independent and age-adjusted normative data for each ability and total CCTI score were also
163 published, with a sample of three hundred eight community-dwelling adults, without cognitive impairment,
164 between 19 and 86 years [24].

165 166 *3.7 Structured Interview for Competency and Incompetency Assessment Testing and Ranking Inventory*

167 The Structured Interview for Competency and Incompetency Assessment Testing and Ranking Inventory
168 (SICIATRI) is a structured interview developed by Kitamura and Kitamura [13] for the assessment of competency
169 in psychiatric patients [13]. SICIATRI is composed by twelve items that measure patient capacity to give informed
170 consent for hospital admission or medication. The items assess the patients' awareness of being informed, do not
171 waive the right to decide, evidence a choice, understanding the right to decide, understanding risks and benefits
172 associated to treatment, alternative treatment or absence of treatment, wanting to get better, the absence of
173 pathological determinants and insight. Answers are rated between 1 and 3, with lower scores representing worst
174 performances. According to the score obtained, patients' performance is rated in one of the five levels of Ranking
175 Inventory for Competency, which ranges from completely incompetent to completely competent. Validation
176 studies included a sample of twenty five psychiatric and twenty three medical hospitalized patients between 21
177 and 80 years [13].

178 179 *3.8 Hopemont Capacity Assessment Interview*

180 Hopemont Capacity Assessment Interview (HCAI) is an interview in a semi-structured format, with two sections.
181 The first section assesses the capacity to make healthcare decisions, and the second measures financial capacity.
182 Only the first section will be considered in the present paper. Being so, HCAI assesses three core abilities:
183 understanding, appreciation and reasoning. The interview starts by presenting the definitions of risk, benefit and
184 having a choice, and next the patients are asked to explain the same definitions in their own words. After that, the
185 interview proceeds with the presentation of two clinical vignettes (eye infection and advance directive), each
186 followed by nine questions. HCAI may be scored by counting the number of correct answers, or assigning scores
187 (0, 1 or 2) to each answer, with higher scores representing more adequate responses. Procedures to calculate total
188 scores are not recommended, since the questions have different weights regarding decision-making capacity [14].

189

190 *3.9 Aid to Capacity Evaluation*

1
2 191 Aid to Capacity Evaluation (ACE) is a semi-structured interview that assesses capacity to make healthcare
3
4 192 decisions, based in patients' real health problem, not a standardized vignette. It evaluates the abilities: to
5
6 193 understand information regarding the medical problem, proposed treatment, its alternatives, and the option of
7
8 194 refusing treatment; reason about the consequences of refusing or accepting the treatment; and appreciation, which
9
10 195 is conceptualized as the ability to make decisions not based on hallucinations, delusions or depression. Each
11
12 196 question is scored as *yes*, if the patient gives an appropriate answer, as *no*, if the patient gives an inappropriate
13
14 197 answer, or as *unsure*, when close-ended questions are necessary. After scoring ACE, the clinician should rate the
15
16 198 patient as definitely capable, probably capable, probably incapable or definitely incapable [15].
17

18 199
19
20 200 *3.10 Vignette method described by Schmand*

21
22 201 Schmand and collaborators [16] studied the usefulness of a vignette method to evaluate capacity to consent to
23
24 202 treatment and research in people with dementia. The pilot study included a sample of 240 subjects, distributed in
25
26 203 control group ($n=176$), minimal dementia ($n=14$), mild dementia ($n=43$) and moderate dementia ($n=7$). The
27
28 204 vignette method consists on the presentation of two clinical vignettes, describing a clinical trial and a hip fracture.
29
30 205 After each vignette being integrally presented, a series of questions are asked. A total of sixteen questions evaluate
31
32 206 understanding, appreciation, reasoning and expressing a choice. After rating patients' answers, competency scores
33
34 207 of each vignette and a combined score may be calculated, by summing the number of correct answers. The authors
35
36 208 [16] established cut-off scores of 95% of the control group mean, which indicate lack of capacity to consent to
37
38 209 treatment and research.
39

40 210
41
42 211 *3.11 Decision Assessment Measure*

43
44 212 Decision Assessment Measure (DAM) is a semi-structured interview designed to evaluate decision-making
45
46 213 capacity in patients with mental disabilities. Target participants were patients who had been advised by their
47
48 214 physicians to have a blood test. The interview begins by asking the patients to say what they know about blood
49
50 215 tests. Then an information sheet about blood tests is presented. After information disclosure, patients are asked a
51
52 216 series of questions that aim to assess their ability to understand and retain information, and to communicate a
53
54 217 choice. When revealing lack of capacity in the first series of questions, each element of the information sheet is
55
56 218 presented at a time and it is followed by questioning and recognition tasks. After the questioning procedure,
57
58 219 patients are asked to perform a non-verbal demonstration, simulating a blood test with medical items. These must
59
60
61
62
63
64
65

220 be chosen by the patient from a set of tools that include distracting items. Answers are rated according to a three-
221 point system (0-2), where greater scores indicate a better performance. Scores should be used to support clinicians'
222 judgment. For study purposes, three clinical samples were considered: group with schizophrenia or schizoaffective
223 disorder ($n=21$), learning disability group ($n=20$), and dementia group ($n=21$) [17].

224

225 *3.12 Capacity Assessment Tool*

226 Capacity Assessment Tool (CAT) was developed to allow a regular and time effective assessment of healthcare
227 decision-making capacity. It enables the assessment of decision-making capacity in real-life situations, so it does
228 not contain clinical vignettes. CAT's score is based on six components, namely, communication, understanding
229 choices, comprehension of risks and benefits, insight, decision process and judgment. Interviewees' answers are
230 scored between 0-3, or 0 and 1. It is not recommended to calculate a total score, so each of the six components
231 must be individually considered. Pilot studies included a sample of twenty patients from a Geriatric Inpatient Unit
232 or Consultation Service [18].

233

234 *3.13. Assessment of Consent Capacity–Treatment*

235 Assessment of Consent Capacity – Treatment (ACC-T) is a structured interview developed to evaluate capacity
236 to consent to treatment in adults with mental retardation. It contains three hypothetical vignettes regarding
237 psychopharmacological treatment, placement of an orthodontic brace and administration of injections to prevent
238 allergic reactions. The vignettes are presented a paragraph at a time, with each being followed by questions that
239 compose a thirteen-item questionnaire. The questionnaire measures the four decisional abilities, and each answer
240 is scored accordingly to a three-point scale (between 0 and 2). There are no indications for calculating a total
241 score, so each ability should be considered individually. Pilot study included a sample of ninety participants
242 distributed in three groups: mild mental retardation, moderate mental retardation and no mental retardation [19].

243

244 *3.14 Vignette method described by Vellinga*

245 Vellinga and collaborators [20] compared three judgments of competency: a vignette method, family members'
246 judgment and physician's judgment. A total of eighty elderly, of whom 37,5% had dementia, their physicians, and
247 eighty family members were included. The vignette method consists on presenting two clinical vignettes (anemia
248 and surgery for colon cancer), followed by a structured interview. The interview assesses understanding,
249 evidencing a choice, reasoning and appreciation. Patients' answers are scored between 0 and 2, with higher scores

250 representing better performance. A total score can be dichotomized into competent or incompetent performance,
1
2 251 by a cut-off score of 95% of the sample without cognitive impairment [20].
3

4 252

6 253 *3.15 Assessment of Capacity to Consent to Treatment*

8 254 The Assessment of Capacity to Consent to Treatment (ACCT) is a semi-structured interview developed to assess
9
10 255 consent capacity in patients with neurocognitive or neuropsychiatric diseases. It evaluates the four abilities of
11
12 256 decision-making, namely understanding, appreciation, reasoning and communicating a choice, as well as values
13
14 257 and preferences relevant to clinical decisions. The ACCT contains three clinical vignettes, the first reporting a
15
16 258 case of rheumatoid arthritis, the second eliciting an advanced directive, and the third describing a leg ulcer. For
17
18 259 clinical use, either the hypothetical vignettes or the patients' real medical problem can be used. In this sense, the
19
20 260 ACCT has the advantage of containing vignettes and also allowing the interview to adapt to real-life situations.
21
22 261 Pilot studies included a control group ($n=19$) and two clinical groups, one with dementia ($n=20$) and other with
23
24 262 schizophrenia ($n=20$). For statistical purposes, Moye et al. (2007) calculated a summary dichotomous score, which
25
26 263 classifies the patient has *has capacity* or *lacks capacity*. To do so, cut-off scores of 2.0 standard deviations from
27
28 264 the control group mean were established for understanding, appreciation and reasoning. Participants who had
29
30 265 scores below the cut-off on any of these abilities had a summary dichotomous score of *lacks capacity* [21].
31

32 266

34 267 **4. Discussion**

36 268 Through this narrative review, seventeen measures of healthcare decision-making capacity were identified.
37
38 269 Although the instruments intended to measure the same construct, they differ on what concerns the competencies
39
40 270 assessed and the methods employed.
41

42 271

44 272 *4.1 Assessed abilities*

46 273 Regarding the competencies assessed, most instruments are based on the four abilities model. However, only eight
47
48 274 instruments assess all the four abilities. Understanding is the only ability measured by all instruments, except for
49
50 275 two which aim to measure specific abilities (POD and TRAT). Understanding is commonly assessed by asking
51
52 276 the patients to paraphrase information disclosed in a hypothetical vignette or regarding their own medical problem.
53
54 277 Appreciation is measured in ten of the seventeen instruments. Nonetheless, there are major differences in how
55
56 278 this ability is assessed. On one hand, CIS, Perceptions of Disorder, MacCAT-T, HCAI and ACE operationalized
57
58 279 appreciation as the acknowledgement of the significance of the information to one's own circumstance,
59

280 recognition of the medical problem and potential benefits from the treatment [25]. In this way, appreciation is
1 understood as insight towards the medical problem and potential benefits of the treatment. On the other hand,
2 281
3 CCTI, Vignette Method by Schman, ACC-T and Vignette Method by Vellinga defined appreciation as the ability
4 282
5 to anticipate emotional and cognitive consequences from the treatment. By that, appreciation is conceptualized as
6 283
7 a foresight capacity, in which the individual should be able to predict changes in his life due to the treatment [26,
8 284
9 27]. These inconsistencies are serious and result in statistical fragilities [21]. To overcome this divergence, the
10 285
11 ACCT assesses appreciation employing two subscales: The Distrust subscale and the Foresight subscale, in an
12 286
13 attempt to consider both of the previous interpretations. In fact, recent definitions of appreciation propose that this
14 287
15 ability implies both the acknowledgment of the medical problem and potential benefits of treatment, and the
16 288
17 anticipation of consequences related to the treatment [26, 28]. Although these recent definitions allow to overcome
18 289
19 the previous challenges on appreciation's conceptualization, they bring another conceptual challenge, discussed
20 290
21 below.

22 291
23 Reasoning assessment is included in eleven instruments, in which the participants are asked to enumerate the risks
24 292
25 and benefits they would have in mind when making a decision, and also to generate consequences of what might
26 293
27 change in their daily lives due to the treatment. When asking patients to generate consequences, reasoning is being
28 294
29 assessed as a foresight ability. However, as discussed before, appreciation as also been defined as the ability to
30 295
31 foresee possible treatment consequences [26]. In this sense, there seems to be a risk of overlapping between
32 296
33 appreciation and reasoning, which should be avoided.

34 297
35 Finally, expressing a choice is contemplated in ten of the seventeen instruments. This ability has been uniformly
36 298
37 measured by asking the participant to choose an option.

38 299
39 A fifth ability, making a reasonable choice, is included in CCTI [12]. The first publications concerning the legal
40 300
41 standards of competence to consent to treatment included this competence [29]. Making a reasonable choice
42 301
43 consisted on the ability to choose the option that a reasonable person would choose. However, this ability has
44 302
45 disappeared from the clinical setting, due to the arbitrariness of what may be considered reasonable. In
46 303
47 fact, Gerstenecker and collaborators [24], instead of *making a reasonable choice*, designates this ability of the
48 304
49 CCTI as *making choice*, which reveals the discontinuity of this ability in capacity assessments.

50 305
51
52 306

53 307 *4.2 Result interpretations*

54 308
55 Apart from the differences on the assessed abilities, the instruments also differ on scoring procedures and
56 309
57 interpretations. In this respect, most of the instruments do not provide instructions for total scores nor cut-off
58
59

310 scores. However, in Two-part Consent Form, the authors [7] computed total scores by summing all item scores.
1
2 311 Also, the authors of the Vignette method by Schmand [16] and the Vignette method by Vellinga [20] calculated
3
4 312 total scores and established cut-off scores for lack of capacity to consent to treatment. Some authors disagree with
5
6 313 this approach, since it assumes that low scores in an ability can be compensated by higher scores in another [30].
7
8 314 The CCTI [12] and the ACCT [21] propose cut-off scores for each ability, stating that the abilities should be
9
10 315 individually considered. According to the four abilities model, in order to have decision-making capacity the
11
12 316 patient must have preserved the four abilities, which may compromise the clinical usefulness of a total score [5].
13

14 317

16 318 *4.3 Information disclosure*

18 319 Another difference between the previous instruments regards the information disclosure, which may consist on
19
20 320 the presentation of a hypothetical situation or the patient's real health problem. On the hypothetical situation, a
21
22 321 clinical vignette describing a fictitious medical problem and treatment options is presented. Conversely, in the
23
24 322 realistic situation patients receive information about their own health problem and treatment options [31]. Both
25
26 323 approaches have advantages and disadvantages. On one hand, standardized clinical vignettes enable the
27
28 324 development of normative data, which are useful in clinical settings and also allow group comparison in research
29
30 325 field [21]. On the other hand, some authors state that decision-making capacity should be evaluated in the context
31
32 326 of the decision at hand, because patients' performance could be different in hypothetical and realistic situations
33
34 327 [30].
35

36 328 Few studies addressed this issue. Grisso and Appelbaum [32] studied the differences between hypothetical and
37
38 329 realistic situations regarding the ability to understand. They found that psychiatric samples showed better
39
40 330 understanding of information related to their own situation. However, non-psychiatric samples performed
41
42 331 similarly in both hypothetical and realistic situations [32]. More recently, Vellinga and collaborators [33] found
43
44 332 no significant differences in mean scores of understanding, appreciation, reasoning and expressing a choice, nor
45
46 333 total mean score, between hypothetical and realistic situations. When comparing groups of impaired and non-
47
48 334 impaired cognitive functioning, cognitive impaired patients performed better on appreciating their own medical
49
50 335 problem and had a significant higher mean on total score. However, no significant differences were found on
51
52 336 understanding, reasoning and expressing a choice [33]. Also, participants with cognitive impairment in the
53
54 337 realistic group received the clinical information twice, which could had contributed to a better performance. These
55
56 338 conclusions stand out the need for more investigation in this field. However, research shows that clinical vignettes
57
58
59
60
61
62
63
64
65

339 can approximate real-life situations [12], and they provide valid information about patients' decision-making
1
2 340 capacity [34], which stands for their usefulness in both research and clinical settings.

3
4 341

5
6 342 *4.4 Healthcare decision-making capacity assessment in cognitive impairment and dementia*

7
8 343 Among the reviewed instruments, three of them were designed to assess consent capacity in the older population,
9
10 344 and five of them to evaluate consent capacity in patients with dementia. When assessing dementia patients'
11
12 345 capacity to consent, it is important to use an instrument that has been specifically developed to assess capacity in
13
14 346 these populations. Mild cognitive impairment and dementia symptoms affect cognitive functions relevant to
15
16 347 decision-making, such as memory, attention and executive functions [35]. Due to this, capacity assessment tools
17
18 348 should include strategies that allow to decrease the demand on such functions. For example, the ACCT, The
19
20 349 Vignette Method by Schman and The Vignette Method by Vellinga include visual aids to reduce memory
21
22 350 demands.

23
24 351 There are other factors which can impact capacity assessments, like the way by which information is presented
25
26 352 [1]. Specifically, framing and phrasing of information can influence the decision-making process. Because of this,
27
28 353 instruments' disclosure of information through clinical vignettes or description of patients' real problems should
29
30 354 be designed in a way that facilitates their understanding of information and maximizes their capacity.

31
32 355 Healthcare values, beliefs and experience are also described as relevant to decision-making [36]. Regarding
33
34 356 capacity assessments, coherence between patients expressed values and their treatment decisions can be an
35
36 357 indication of capacity, and research has shown that people with dementia appear to express their values as
37
38 358 consistently as elderly without cognitive impairment [37]. However, only ACCT includes values assessment.

39
40 359 When comparing assessment instruments' targeting older adults or patients with dementia, it is possible to identify
41
42 360 discrepancies among the assessed abilities. Furthermore, research has identified significant differences in capacity
43
44 361 assessment results between different assessment tools. In this respect, Moye and collaborators [27] compared the
45
46 362 results of CCTI, MacCAT-T and HCAI in a sample of elders with mild to moderate dementia and matched control
47
48 363 groups. Study results showed differences on appreciation and reasoning assessments. Specifically, participants
49
50 364 with dementia performed worse than control groups on appreciation when measured by CCTI, but according to
51
52 365 MacCAT-T and HCAI. Similarly, participants with dementia performed worse than control group participants on
53
54 366 reasoning, when measured by MacCAT-T and CCTI, but not when assessed by HCAI [27]. These inconsistencies
55
56 367 reveal the need for more study in this area, in order to improve assessment tools' reliability.

368 Another relevant improvement to healthcare decision-making capacity assessment would be the development of
1 normative data. According to the research conducted, only CCTI developed normative data [24]. Nevertheless,
2 369
3
4 370 undertaking more normative studies could be a valuable contribution to increase capacity assessments precision.
5
6 371 Normative data provide a point of reference from which patients' performance can be compared to. Knowing
7
8 372 what level of performance is expected for an adult within a specific age range or education level can give
9
10 373 additional information about the patients' capacity impairment, and therefore improve assessments accuracy.

11 374

14 375 **5. Conclusion**

16 376 Concerns about healthcare decision-making capacity will continue to grow world widely, since the prevalence of
17
18 377 dementia and other diseases related to cognitive impairment keeps increasing. One of the most relevant topics in
19
20 378 this field relates to the way capacity should be conceptualized. On one hand, clinical approaches conceptualize
21
22 379 healthcare capacity as a gradual model, according to which the patient can vary among levels of competence. In
23
24 380 this model, a person may retain capacity to consent to routine procedures, but lack competence to make decision
25
26 381 about risky treatments. On the other hand, in legal settings healthcare capacity is predominantly considered a
27
28 382 threshold competence, this is, either the person is considered to have or not have capacity to make healthcare
29
30 383 decisions [28]. A gradual model is undoubtedly more congruent with how capacity varies in real life situations,
31
32 384 where competence does not appear as a dichotomous construct [34]. However, it can be challenging to apply this
33
34 385 approach in legal settings, where a specific judgment is required.

36 386 This review shows that a considerable number of instruments to assess decision-making capacity have been
37
38 387 developed in the last decades. However, decision-making capacity in healthcare still lacks a gold standard [38].
39
40 388 In consequence, clinical judgment is still considered as the closest to a gold standard of capacity assessment [1].
41
42 389 Nonetheless, clinical judgment, without the recourse of a standardized assessment tool, has been proved to
43
44 390 overestimate patients' capacity to make healthcare decisions [39]. Alternatively, the Mac-CAT has been pointed
45
46 391 out has a gold standard in decision-making capacity assessment [40]. Although Mac-CAT is one of the most
47
48 392 widely used instruments, some restraints must be considered, as the lack of normative data.

50 393 Assessment of healthcare decision-making capacity raises a few unanswered challenges. A further develop of
51
52 394 standardized tools, with normative data, and more widespread education and training in capacity assessment
53
54 395 among psychologists and other mental health professionals are needed to achieve more accurate assessments.
55
56 396 Standardized tools development should be based on a thoroughly review of relevant literature and previous
57
58
59
60
61
62
63
64
65

397 assessment tools. Likewise, instruments development should consider experts experiences and practices, as well
1
2 398 as gather professionals' perspectives on how to assess healthcare decision-making capacity.

3
4 399 Furthermore, it is considered that in order to improve healthcare decision-making capacity assessments'
5
6 400 reliability, clear legal frameworks and guidelines regarding capacity assessments are necessary. To our view,
7
8 401 assessments of healthcare decision-making capacity should follow specific legal procedures or guidelines that
9
10 402 define assessment protocols, including a valid standardized capacity assessment tool with normative data, as well
11
12 403 as a broader neuropsychologic assessment. The definition of guidelines seems to be a necessary condition to
13
14 404 protect patients' rights of autonomy and protection.

15
16 405

17 18 406 **6. Bibliography**

19
20 407 1. Moye J, Gurrera RJ, Karel MJ, Edelstein B, O'Connell C. Empirical advances in the assessment of the
21
22 408 capacity to consent to medical treatment: Clinical implications and research needs. *Clin Psychol Rev.* 2006;
23
24 409 <https://doi.org/10.1016/j.cpr.2005.04.013>

25
26 410 2. Galietta M, Garcia-Mansilla A, Stanley B (2013) *Assessing Civil Capacities*. In: Weiner IB, Otto RK editors.
27
28 411 *Handbook of Forensic Psychology*, 4th ed. New Jersey: John Wiley & Sons; 2013. pp. 219–236

29
30 412 3. Grisso T, Appelbaum PS. *Assessing Competence to Consent to Treatment: A Guide for Physicians and Other*
31
32 413 *Health Professionals*. New York: Oxford University Press; 1998.

33
34 414 4. Palmer BW, Salva GN, Harmell AL. *Healthcare Decision-Making Capacity*. In: Demakis GJ, editor. *Civil*
35
36 415 *Capacities in Clinical Neuropsychology*. New York: Oxford University Press; 2012. pp. 69–94

37
38 416 5. Appelbaum P, Grisso T. *Assessing patients' capacities to consent to treatment*. *N Engl J Med.* 1988;
39
40 417 <https://doi.org/10.1056/NEJM198812223192504>

41
42 418 6. Palmer BW, Harmell AL. *Assessment of Healthcare Decision-making Capacity*. *Arch Clin Neuropsychol.*
43
44 419 2016; <https://doi.org/10.1093/arclin/acw051>

45
46 420 7. Roth LH, Lidz CW, Meisel A, Soloff PH, Kaufman K, Spiker DG, Foster FG. *Competency to decide about*
47
48 421 *treatment or research*. *Int J Law Psychiatry.* 1982; [https://doi.org/10.1016/0160-2527\(82\)90013-9](https://doi.org/10.1016/0160-2527(82)90013-9)

49
50 422 8. Fitten JL, Waite MS. *Impact of Medical Hospitalization on Treatment Decision-Making Capacity in the*
51
52 423 *Elderly*. *Arch Intern Med.* 1990;150:1717–1721

53
54 424 9. Bean G, Nishisato S, Rector NA, Glancy G . *The psychometric properties of the Competency Interview*
55
56 425 *Schedule*. *Can J Psychiatry.* 1994; <https://doi.org/10.1177/070674379403900804>

57
58 426 10. Grisso T, Appelbaum PS, Mulvey EP, Fletcher K. *The MacArthur Treatment Competence Study. II -*
59
60
61
62
63
64
65

- 427 Measures of abilities related to competence to consent to treatment. *Law Hum Behav.* 1995;
 1
 2 428 <https://doi.org/10.1007/BF01499322>
 3
 4 429 11. Grisso T, Appelbaum PS (1998) *MacArthur Competence Assessment Tool For Treatment (MacCAT-T)*.
 5
 6 430 Sarasota: Professional Resource Press; 1998.
 7
 8 431 12. Marson DC, Ingram KK, Cody HA, Harrell LE. Assessing the Competency of Patients With Alzheimer's
 9
 10 432 Disease Under Different Legal Standards A Prototype Instrument. *Arch Neurol.* 1995;
 11
 12 433 <https://doi.org/10.1001/archneur.1995.00540340029010>
 13
 14 434 13. Tomoda A, Yasumiya R, Sumiyama T, Tsukada K, Hayakawa T, Matsubara K, Kitamura F, Kitamura T.
 15
 16 435 Validity and reliability of structured interview for competency incompetency assessment testing and ranking
 17
 18 436 inventory. *J Clin Psychol.* 1997; [https://doi.org/10.1002/\(SICI\)1097-4679\(199708\)53:5<443::AID-](https://doi.org/10.1002/(SICI)1097-4679(199708)53:5<443::AID-)
 19
 20 437 [JCLP4>3.0.CO;2-O](https://doi.org/10.1002/(SICI)1097-4679(199708)53:5<443::AID-JCLP4>3.0.CO;2-O)
 21
 22 438 14. Edelstein B. Challenges in the assessment of decision-making capacity. *J Aging Stud.* 2000;
 23
 24 439 [https://doi.org/10.1016/S0890-4065\(00\)80006-7](https://doi.org/10.1016/S0890-4065(00)80006-7)
 25
 26 440 15. Etchells E, Darzins P, Silberfeld M, Singer PA, Mckenny J, Naglie G, Katz M, Guyatt GH, Molloy DW,
 27
 28 441 Strang D. Assessment of Patient Capacity to Consent to Treatment. *J Gen Intern Med.* 1999; [https://doi.org/](https://doi.org/10.1046/j.1525-1497.1999.00277.x)
 29
 30 442 [10.1046/j.1525-1497.1999.00277.x](https://doi.org/10.1046/j.1525-1497.1999.00277.x)
 31
 32 443 16. Schmand B, Gouwenberg B, Smit J, Jonker C. Assessment of mental competency in community-dwelling
 33
 34 444 elderly. *Alzheimer Dis Assoc Disord.* 1999; <https://doi.org/10.1097/00002093-199904000-00004>
 35
 36 445 17. Wong JG, H Clare IC, Holland AJ, Watson PC, Gunn M. The capacity of people with a "mental disability"
 37
 38 446 to make a health care decision. *Psychol Med.* 2000; <https://doi.org/10.1017/s0033291700001768>
 39
 40 447 18. Carney M, Neugroschl J, Morrison S, Marin D, Siu A. The development and Piloting of a Capacity
 41
 42 448 Assessment Tool. *Artic J Clin ethics.* 2001;12:17–23
 43
 44 449 19. Cea CD, Fisher CB. Health Care Decision-Making by Adults With Mental Retardation. *Ment Retard.* 2003;
 45
 46 450 [https://doi.org/10.1352/0047-6765\(2003\)041<0078:hcdmba>2.0.co;2](https://doi.org/10.1352/0047-6765(2003)041<0078:hcdmba>2.0.co;2)
 47
 48 451 20. Vellinga A, Smit JH, van Leeuwen E, van Tilburg W, Jonker C. Competence to consent to treatment of
 49
 50 452 geriatric patients: Judgements of physicians, family members and the vignette method. *Int J Geriatr*
 51
 52 453 *Psychiatry.* 2004; <https://doi.org/10.1002/gps.1139>
 53
 54 454 21. Moye J, Karel MJ, Edelstein B, Hicken B, Armesto JC, Gurrera RJ. Assessment of capacity to consent to
 55
 56 455 treatment. *Clin Gerontol.* 2007;31:37-66
 57
 58 456 22. Grisso T, Appelbaum PS. The MacArthur Treatment Competence Study. III: Abilities of patients to consent
 59
 60
 61
 62
 63
 64
 65

- 457 to psychiatric and medical treatments. *Law Hum Behav.* 1995; <https://doi.org/10.1007/BF01499323>
- 1
2 458 23. Appelbaum PS, Grisso T. The MacArthur treatment competence study. I: Mental illness and competence to
3
4 459 consent to treatment. *Law Hum Behav.* 1995; <https://doi.org/10.1007/BF01499321>
- 5
6 460 24. Gerstenecker A, Niccolai L, Marson D, Triebel KL. Enhancing Medical Decision-Making Evaluations:
7
8 461 Introduction of Normative Data for the Capacity to Consent to Treatment Instrument. *Assessment.* 2016;
9
10 462 <https://doi.org/10.1177/1073191115599053>
- 11
12 463 25. Sturman ED. The capacity to consent to treatment and research: A review of standardized assessment tools.
13
14 464 *Clin Psychol Rev.* 2005; <https://doi.org/10.1016/j.cpr.2005.04.010>
- 15
16 465 26. Kolva E, Rosenfeld B. Legal Perspectives on Civil Capacity and Competence. In: Demakis GJ, editor. *Civil*
17
18 466 *Capacities in Clinical Neuropsychology.* New York: Oxford University Press; 2012. pp. 17–36
- 19
20 467 27. Moye J, Karel MJ, Azar AR, Gurrera RJ. Capacity to Consent to Treatment: Empirical Comparison of Three
21
22 468 Instruments in Older Adults With and Without Dementia. *Gerontologist.* 2004;
23
24 469 <https://doi.org/10.1093/geront/44.2.166>
- 25
26 470 28. American Bar Association Commission on Law and Aging, American Psychological Association. *Assessment*
27
28 471 *of older adults with diminished capacity: A handbook for psychologists;* 2008.
29
30 472 <https://www.apa.org/pi/aging/programs/assessment/capacity-psychologist-handbook.pdf>
- 31
32 473 29. Roth LH, Meisel A, Lidz CW. Tests of competency to consent to treatment. *Am J Psychiatry.* 1977;
33
34 474 <https://doi.org/10.1176/ajp.134.3.279>
- 35
36 475 30. Grisso T. Competence to Consent to Treatment. In: Grisso T, Borum R, Edens J, Moye J, Otto R, editors.
37
38 476 *Evaluating Competencies: Forensic Assessments and Instruments,* 2nd ed. New York: Springer; 2005. pp.
39
40 477 391–460
- 41
42 478 31. Thalén L, Heimann Mühlenbock K, Almkvist O, Eriksdotter M, Sundström E, Tallberg IM. Do adapted
43
44 479 vignettes improve medical decision-making capacity for individuals with Alzheimer’s disease? *Scand J*
45
46 480 *Psychol.* 2017; <https://doi.org/10.1111/sjop.12401>
- 47
48 481 32. Grisso T, Appelbaum P. Mentally ill and non-mentally-ill patients’ abilities to understand informed consent
49
50 482 disclosures for medication - Preliminary data. *Law Hum Behav.* 1991; <https://doi.org/10.1007/BF02074077>
- 51
52 483 33. Vellinga A, Smit JH, Van Leeuwen E, Van Tilburg W, Jonker C. Decision-making capacity of elderly
53
54 484 patients assessed through the vignette method: Imagination or reality? *Aging Ment Heal.* 2005;
55
56 485 <https://doi.org/10.1080/13607860512331334059>
- 57
58 486 34. Vellinga A, Smit J, van Leeuwen E, van Tilburg W, Jonker C. Instruments to assess decision-making
59
60
61
62
63
64
65

- 487 capacity: an overview. *Int Psychogeriatrics*. 2004; <https://doi.org/10.1017/s1041610204000808>
- 1
2 488 35. Marson DC. Loss of competency in Alzheimer's disease: Conceptual and psychometric approaches. *Int J*
3
4 489 *Law Psychiatry*. 2001; [https://doi.org/10.1016/S0160-2527\(01\)00064-4](https://doi.org/10.1016/S0160-2527(01)00064-4)
- 5
6 490 36. Russo S, Jongerius C, Faccio F, et al. Understanding Patients' Preferences: A Systematic Review of
7
8 491 Psychological Instruments Used in Patients' Preference and Decision Studies. *Value Heal*. 2019;
9
10 492 <https://doi.org/10.1016/j.jval.2018.12.007>
- 11
12 493 37. Karel MJ, Moye J, Bank A, Azar AR. Three Methods of Assessing Values for Advance Care Planning:
13
14 494 Comparing Persons With and Without Dementia. *J Aging Health*. 2007;
15
16 495 <https://doi.org/10.1177/0898264306296394>
- 17
18 496 38. Pennington C, Davey K, Meulen R Ter, Coulthard E, Kehoe PG. Tools for testing decision-making capacity
19
20 497 in dementia. *Age Ageing*. 2018; <https://doi.org/10.1093/ageing/afy096>
- 21
22 498 39. Sessums LL, Zembrzuska H, Jackson JL. Does this patient have medical decision-making capacity? *JAMA*
23
24 499 - *J Am Med Assoc*. 2011; <https://doi.org/10.1001/jama.2011.1023>
- 25
26 500 40. Sturman ED. The capacity to consent to treatment and research: A review of standardized assessment tools.
27
28 501 *Clin Psychol Rev*. 2005; <https://doi.org/10.1016/j.cpr.2005.04.010>
- 29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60
61
62
63
64
65