

## *Supplementary Materials for*

# The evaluation of capacity in dementia: ethical constraints and best practice. A systematic review

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Search of the literature focused only on systematic and major reviews, carried out using PubMed, PCM and Cochrane Library databases. The following keywords were entered: [dementia] AND [decision-making] or [competence evaluation] or [informed consent] or [ethics] or [testamentary capacity] or [Testamentary capacity evaluation] AND [review] or [systematic review].

Authors	Publication year	Article	Search methods	Brief description
Freedman M, Stuss D, Gordon M [32]	1991	Review	Not specified	Set of guidelines for assessing cognitive functions that underlie competency. Focus on neurobehavioural deficits.
High D [28]	1994	Review	Not specified	Guidelines and standards for assessing decision making capacity/incapacity
Kim S, Karlawish J, Caine E [21]	2002	Systematic review Thematic analysis	MEDLINE, Bioethics Line, PsycINFO. 32 studies, from 1966 to 2001	Incapacity is common in Alzheimer disease, but many people with dementia can make their own medical and research decisions. Memory and executive-function deficits predict decisional impairment.
Fellows L [31]	2004	Review	Not specified	Exploring the cognitive neuroscience of human decision making with a focus on the roles of the frontal lobes.
Sullivan K [43]	2004	Systematic review	Not specified	Neuropsychological tasks to assess general cognitive function are recommended. A two-stage model for the cognitive assessment of capacity is proposed.
Sturman E [35]	2005	Review	Not specified	Many of the instruments available measure all of the abilities relevant to competency. The majority of instruments, apart from the MacCAT-T, MacCAT-CR, and CCTI, require further testing.
Woods B, Pratt R [90]	2005	Narrative review	Not specified	Competency and awareness are multi-faceted. Competence in dementia is closely related to the recognition of awareness.
Dunn L, <i>et al.</i> [66]	2006	Critical review Psychometric analysis	PubMed, PsycINFO, Article First, Lexis Nexis, Westlaw. 23 studies from Jan 1980 to Dec 2004	The MacCAT-T and -CR are the best choices for measuring the capacity to consent to treatment and research, given their comprehensiveness and supporting psychometric data
Moye J, <i>et al.</i> [65]	2006	Review	Not specified	The lack of a gold standard for capacity assessment hampers the establishment of valid instruments. Sample characteristics (disease subtype, stage and treatment) could be associated with divergent findings. Rarity of studies that apply similar methodologies across multiple well defined patient groups.
Moye J, Marson D [61]	2007	Review	Not specified 16 studied from 1988 to 2001	Capacity to consent declines as dementia progresses. Loss of capacity over time is due to declining reasoning, and is predicted by earlier problems with naming, verbal memory, and mental flexibility.
Palmer B, Savla G [60]	2007	Critical systematic review Bivariate correlations	PubMed, Medical subject Headings, PsycINFO. 15 studies between 1997 and 2006	The magnitude of the correlation between capacity and neuropsychological scores varies between studies, but a significant relationship between scores is present across all of the studies.
Slaughter S, <i>et al.</i> [44]	2007	Review	Not specified	Practical guidelines for the recruitment of people in the middle or late stages of dementia are proposed, to be used in a minimal risk study.
Lai JM, Karlawish J [17]	2007	Clinical review	Not specified	Current approaches to assess patients' capacity in decision-making are limited. A semi-structured interview for the assessment of everyday decision making is proposed. Practical clinical tools should be implemented to improve both the accuracy and consistency of assessments.
Jacoby R, Steer P [73]	2007	Review	Not specified	Increasing age and cases of dementia are leading to more contested wills. Doctors who have to certify the testamentary capacity of testators need to know the legal tests for TC. Examinations based on the legal tests are more likely to avoid future litigation.
Karlawish J [92]	2008	Review	Studies performed in author's Lab	Among persons with very mild- to moderate-stage Alzheimer's disease, there is relative preservation of the abilities to choose and reason, compared to the abilities to understand and appreciate.

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Gleichgerrcht A, <i>et al.</i> [22]	2010	Clinical review	Not specified. 24 studies on AD, FTD, PD and HD	Recommendations for future studies to aid the understanding of decision-making cognition.
Appelbaum P [40]	2010	Review	Not specified. Studies published in 2002 and later	People with MCI can show significant impairment in consent-related functions, but retain sufficient capacity to make valid treatment and research decisions
Sessums, <i>et al.</i> [58]	2011	Systematic review Linear mixed analysis	MEDLINE, EMBASE. 43 prospective studies until 2011	Incapacity is common in healthy elderly people (95% CI, 1.7%-3.9%). MMSE scores less than 20 increase the likelihood of incapacity (95% CI, 3.7-11). The ACE is useful in assessments of decision making capacity (95% CI, 3.9-19).
Kim S [25]	2011	Review	Not specified	No clear-cut line exists between capacity and incapacity. Ethically relevant abilities may be preserved in incapacitated patients with dementia, who can be enrolled in research in ways that are consistent with their values.
Widera E, <i>et al.</i> [18]	2011	Review	MEDLINE, PsycINFO, CINAHL, Cochrane database. Articles from 1966 to June 2010	Patients with mild AD show global impairments of both simple and complex financial skills. Timely identification and an informal assessment of financial impairment can lead to financial protection and can limit the economic and legal hardships of financial incapacity.
Lamont S, Jeon YH, Chiarella M [70]	2012	Integrative review Thematic analysis	MEDLINE, PsycINFO, Embase, CINAHL, Scopus. 19 studies, between Jan 2005 and Dec 2010	Reviewed instrument shows limitations in validity and reliability. The absence of a standardised definition for capacity assessment compromises the development of a "gold standard" instrument.
Kennedy K [84]	2012	Review	Not specified	Synthesis of literature to guide medical practitioners in the assessment of testamentary capacity.
Roof J [72]	2012	Review	Not specified	Two key areas: testamentary capacity and guardianship assessments. Evaluators should screen for physical, emotional and financial abuse in the evaluations of elderly patients.
Kirshner H [67]	2013	Brief review	Not specified	The CCTI, along with the MMSE, may be helpful in determining competency in patients with dementia.
Strech D, <i>et al.</i> [97]	2013	Systematic qualitative review. Qualitative text analysis and normative analysis	MEDLINE, Google books. German and English Literature from Jan 2000 to Jan 2011 (92 studies)	Seven main types of spectrum of disease-specific ethical issues in dementia are identified. General ethical principles need specifications to assist medical decision making in all its different steps.
Rosen, <i>et al.</i> [98]	2014	Brief review	Not specified	Reviews that highlight empirical findings from within or outside AD research can catalyse the resolution of controversial topics.
Fields L, Calvert J [50]	2015	Review	AMA, Google Scholar, PsycINFO	Ongoing evaluations of competence and consent ensures that patients' functioning and needs are considered, and that providers are adhering to ethical standards and best practices.
Johnson R, Karlawish J [36]	2015	Review	Not specified	An integrative approach is necessary to analyse the ethical, legal, and social implications of dementia research. Dementia raises ethical questions broader than medical research and care, requiring the expertise of non-medical disciplines.
Lepping P [20]	2015	Systematic review and meta-analysis	Embase, MEDLINE and PsycINFO. 58 studies until Nov 2013	The average percentage of patients with incapacity is 45% on psychiatric wards and 34% in medical settings, with higher levels of incapacity in learning disability, delirium and neurological disease.
Kauffman P [75]	2016	Review – legal cases	Not specified	Representative cases from three USA jurisdictions. Neuropsychological consultation in civil capacity cases is an emerging area of expertise.

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Sudo F, Laks J [23]	2017	Systematic review and meta-analysis	MEDLINE, ISI Web of Knowledge, LILACS, PsycINFO. 10 studies, between 1999 and 2014	Financial judgement impairment parallels the AD progression. Frontal lobe volumes account for any variance expressed in FCI total scores in a regression model.
Spreng R, <i>et al.</i> [19]	2016	Review	Not specified	Age-related changes in decision-making capacities can influence the risk of exploitation in the elderly. Research needs to narrow the gap between the neural mechanisms of decision-making and the assessment of financial competence in the real world.
Palmer B, Harmell A [4]	2016	Review	Not specified	Evaluating the capacity to consent to treatment must consider all four dimensions of this construct: Understanding, Appreciation, Reasoning, and the Expression of a Choice. Psychologists should enhance the capacity of the individual to meaningfully participate in healthcare decision-making.
Wood S, Lichtenberg P [62]	2017	Review	Not specified	Cognitive abilities underlie financial management and their decline compromises financial decision making, thus resulting in susceptibility to financial exploitation. A model that integrates contextual and cognitive factors is proposed.
Darby R, Dickerson B [12]	2017	Literature review	Not specified	Decision-making is a complex process, depending on multiple executive functions. Traditional cognitive tests may not fully evaluate the decisional processes and should be incorporated with other measures.
Davis R, <i>et al.</i> [27]	2017	Integrative review Thematic analysis	CINAHL, PubMed, Google Scholar. 12 studies from Jan 2000 to Nov 2016	Individuals with AD can make some decisions about everyday activities and can express their desires accurately. Decisions regarding end-of-life care, health care, finances and living arrangements have important ramifications regarding safety and well-being.
West E, <i>et al.</i> [46]	2017	Systematic review Content analysis	MEDLINE, PsycINFO, Cochrane Library, Web of Science, Sociological Abstracts, CINAHL. 29 studies between 1995 and 2013	Lack of consensus in current research guidelines addressing the ethical concerns about the interests of the individuals with dementia and protection of their vulnerabilities and rights.
Gilbert T, <i>et al.</i> [45]	2017	Narrative review	PubMed, Cochrane Library, Google Scholar. 19 publications, from Nov 2015 to Apr 2017	The MacCAT-CR is the best-validated questionnaire. The UBACC seems useful for routine practice because of its simplicity, relevance, and applicability in older patients.
Voskou P, <i>et al.</i> [71]	2018	Systematic review	MEDLINE/PubMed. Articles and books from 1980 to 2017	Significant methodological difficulties when assessing TC in a standardised way. A widely accepted instrument has not yet been developed; the ideal battery of tests should have excellent sensitivity and relatively short duration.
Van Duinkerken E, <i>et al.</i> [59]	2018	Systematic review	PubMed, PsycINFO, and Web of Science. 22 studies from Jan 2000 to Oct 2017	Decision-making is impaired in AD, but the cognitive and neuronal correlates of this process are poorly studied. Lower MMSE scores are related to poorer decision making capacities.
Pennington C, <i>et al.</i> [34]	2018	Systematic review Comparative method with UK legislation	Pubmed. 57 studies between 2000 and 2017	Multiple instruments for assessing capacity exist, but none is universally accepted. A combination of the opinion of a healthcare professional trained in capacity evaluation, <i>plus</i> a structured assessment tool is the most robust approach.
Brenkel M, <i>et al.</i> [77]	2018	Review	PsycINFO, MEDLINE. 47 studies from 1946 to 2016	No standardised tool for the clinical assessment of TC can act as a CAI based on clear legal criteria, nor are there any cognitive models. In complex cases, a CAI should include a neuropsychological assessment.

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Authors	Publication year	Article	Search methods	Brief description
Bhatt J, <i>et al.</i> [24]	2018	Systematic review with narrative synthesis	MEDLINE, PsycINFO, HAPI, EBSCO, CINAHL. 15 studies from 1997 to 2017	Four styles of decision making in AD, PD and stroke patients. Factors influencing decisional involvement include background and contextual factors.
Zuskak S, <i>et al.</i> [74]	2019	Methodology review	Legislation in Queensland state (AUS)	Need for validated protocols to assess decision making capacity: which cognitive tests best predict capacity and what testing protocol best adheres to scientifically and legally appropriate standards of evidence?

ACE: Aid to Capacity Evaluation; AD: Alzheimer's Disease; CAI: Contemporaneous Assessment Instrument; CCTI: Capacity to Consent to Treatment Instrument; FCI: Financial Capacity Instrument; MacCAT-CR: MacArthur Competence Assessment Tool for Clinical Research; MacCAT-T: MacArthur Competence Assessment Tool for Treatment; MC: Mild Cognitive Impairment; MMSE: Mini-Mental State Examination; PD: Parkinson's Disease; TC: Testamentary Capacity; UBACC: University of California Brief Assessment of Capacity to Consent.