A Review of the Literature on Capacity Assessment Tools within Mental Health Practice

Briefing Document

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With conceptual guidance and feedback from the Mental Health and Addictions Subgroup of the JCB Task Force on Medical Assistance in Dying (MAID)

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Background & Rationale

Under the leadership of the University of Toronto Joint Centre for Bioethics (JCB), an interdisciplinary task force was assembled to anticipate and respond to the ethical considerations in the implementation of Medical Assistance in Dying (MAID) in Canada. One of the mandates of the mental health and addictions subgroup of the task force was to identify and understand the capacity assessment process for MAID requests involving persons with an underlying mental health diagnosis.

Cursory searches within the literature and scoping exercises with clinicians made it apparent that great variability exists in the capacity assessment process and tools utilized in psychiatric practice. Through on-going work by the JCB Task Force, coupled with evolving practice, capacity assessment for MAID requests has been recognized as an area requiring more standardization as well as deeper ethical consideration. In order to explore the ethical challenges involved with capacity assessment for MAID requests, a scoping of the literature was conducted to better understand the range of capacity assessment tools described within psychiatric populations.

This briefing document summarizes some of the preliminary findings of the review. The goal is not to suggest a new tool or modify an existing one. Rather, it is to provide ethicists and clinicians the opportunity to share ethical and practical concerns about the robustness of capacity assessments in order to consider how existing processes may be adapted and standardized, particularly in the context of MAID.

Overarching Questions

Research questions were developed with the aim of keeping the literature search iterative. Accordingly, the review is guided by three overarching questions and various sub-points that will be more fully described in a future publication.

Q1. What are the various capacity assessment tools described in the academic literature for use within mental health practice?

Q2. Has the capacity assessment tool been used in clinical contexts within psychiatry that may be analogous to a MAID case?

Q3. Are there any unique considerations or additional guiding questions in assessing capacity that should be highlighted for MAID?

Summary of Emerging Findings

Fifty articles have been included for review, and collectively span jurisdictions from Australia, Canada, Europe, UK, and US.

Articles critically appraising standardized capacity assessment tools present overlapping information on the capacity assessment tools available, definition of capacity utilized, format of assessment, domains of capacity assessed, patient populations tested, measures of validity, and limitations of the tools. Several of the emerging findings are provided below for each of these common overlapping themes:

Capacity assessment tools available

In the reviewed literature, 24 capacity assessment tools that have been described, 12 of which were developed for use in the mental health context. Refer to **Appendix A** for a list of the described tools.

Definition of capacity utilized

- Most studies describing or validating a capacity assessment tool begin by defining capacity in the context of decision-making for a specific clinical treatment or voluntary admission to a psychiatric facility.
- Although some clarify capacity as falling on a continuum for certain clinical diagnoses, most tools report the finding of capacity as binary, i.e., capacity reported as present or absent.

Format of assessment

- Capacity assessment tools broadly follow two formats: structured format questionnaire and semi-structured format questionnaire. Either format may be accompanied by clinical vignettes or case studies. The vignette style format encourages clarification of clinical facts and patient education prior to assessment.

Domains of capacity assessed

- Four domains of capacity assessment are consistently described across the included articles: *understanding*, *appreciation*, *reasoning*, and *communicating back a choice*. Only 12 tools include assessments for all four domains.
- Additional sub-domains have not been not identified, although two tools, the Assessment of Capacity to Consent to Treatment (ACCT) and the Regional Capacity Assessment Team (RCAT) tool, include sections for psychosocial assessments (Moye et al, 2008; Newberry & Pachet, 2008).
- The MacArthur Competence Assessment Tool for Treatment (MacCAT-T) has been reviewed, validated, and often described by many articles as the "gold standard" capacity assessment tool for psychiatric treatment and decision-making. Articles seeking to validate a tool often utilized the MacCAT-T as a standard comparator.

Patient populations tested

- Across the described tools, patient populations validated include diagnoses of schizophrenia & schizoaffective disorders, major depressive disorder, bipolar disorder, dementia including vascular etiologies, eating disorders (primarily anorexia nervosa), as well as among forensic populations.
- Addictions have not been explicitly addressed by any of the included studies on capacity assessment tools or reviews, either as a primary diagnosis.

Measures of validity

- Data on validity and reliability are not consistently available for all tools, which impedes standardized comparisons of reliability.
- Validation of tools are reported by a) comparison against one or more existing tools, b) against an expert judgment, or c) by testing between a control group and specific patient populations.
- There is no clarification on the eligibility measures that deem one physician or psychiatrist an expert.

Limitations of tools

- ***Assessor bias:*** The tools described tend to rely on the assessor's judgment, and ensuing bias has been particularly identified in risk-averse clinical environments.

- ***Broad variations in interpreting domains:*** The variation in interpretation is particularly evident for the domains of *reasoning* and *appreciation*. The tools do not address the practical difficulties one might face when trying to assess abilities for seeking information, consequential thinking, complex thinking, and probabilistic thinking.
- ***Limited sample size:*** Where data is available, the sample size does not exceed 100.
- ***Lack of test measures to include psychosocial context:*** Across the tools, there is insufficient data to suggest that the psychosocial context of the patient is adequately considered in the capacity assessment process. Only two tools, the Assessment of Capacity to Consent to Treatment (ACCT) and the Regional Capacity Assessment Team tool (RCAT), included explicit sections for psychosocial test measures (Moye et al 2008; Newberry & Pachet, 2008).

Searches to identify any clinical scenarios that might be potentially analogous to MAID in terms of capacity assessment for complex decision-making, have not yielded particular results. None of the included articles describe end-of-life scenarios or decision-making for palliative care where a mental health diagnosis is present.

One article by Werth et al (2000) describes in detail the clinical process recommended in Oregon and other U.S states permitting assisted dying. As part of the capacity assessment process, the MacCAT-T tool has been mentioned along with several other neuropsychological and cognitive tests.

Preliminary Analysis

The ethical analysis of the findings from the review is guided by the overarching ethical principles and associated goals outlined in the JCB discussion paper, "An Ethics-based Analysis and Recommendations for Implementing Physician-Assisted Dying in Canada". While a comprehensive analysis is beyond the scope of this briefing document, some preliminary recommendations are emerging.

A notable limitation described across the tools was the heavy reliance on the assessor's skills and experience. This ought to be seriously reflected upon when exploring broader solutions for standardized capacity assessment processes.

One of the more notable differences between the capacity assessment process for more conventional treatment and that for MAID is the consequence of the decision (Grisso & Appelbaum, 1998). Assessments of capacity for treatment decisions typically favor life as a benefit, and death a risk. An intentional choice for death can be antithetical to commonly understood risk and benefit assessments. Subsequently, all capacity assessment tools were developed to follow these medical and social conventions as the implicit framework within which the seriousness of a patient's choice may be assessed. Yet, the evolving landscape of legal and moral acceptability for assisted dying calls

for re-envisioning social norms, and revising clinical instruments to appropriately suit the capacity assessment objectives and context (Werth et al, 2000).

Accordingly, interpretations of the four domains for capacity assessment, as well as the risks, benefits, and the consequences of decision-making, may need to be revisited for particular application in the context of MAID.

A key ethical principle is that of justice which means that like cases should be treated alike and dissimilar cases treated in a way that reflects the dissimilarities. It warrants further consideration as to whether the lack of standardization among existing capacity assessment tools is truly reflective of the dissimilarities or poses deeper justice issues. These preliminary findings underscore the need to standardize the validation of capacity assessment tools which is particularly relevant in the high-stakes context of MAID.

Conclusion

The findings from this review are meant to be a first step in calling for collaboration between ethicists & clinicians. The emphasis going forward would be on the need for sustained commitment to working towards achieving the highest ethical standards & clinical skills.

Appendix A: List of Capacity Assessment Tools

Tools in boldface text were developed for use within mental health populations.

1. Aid to Capacity Evaluation (ACE)
2. **Assessment of Capacity to Consent to Treatment (ACCT)**
3. Brief Informed Consent Test
4. **California Scale of Appreciation (CSA)**
5. Capacity Assessment Tool (CAT)
6. **Capacity to Consent to Treatment Instrument (CCTI)**
7. Competency Assessment Interview (CAI)
8. **Competency Interview Schedule (CIS)**
9. Competency Questionnaire (CQ)
10. CURVES framework
11. Decision Assessment Measure (DAM)
12. Hopemont Capacity Assessment Interview (HCAI)
13. **Hopkins Competency Assessment Test (HCAT)**
14. **MacArthur Competence Assessment Tool—Treatment (MacCAT-T)**
15. **Original MacArthur treatment competence study- Understanding Treatment Disclosures (UTD)**
16. **Original MacArthur treatment competence study- Perceptions Of Disorder (POD)**
17. **Original MacArthur treatment competence study- Thinking Rationally About Treatment (TRAT)**
18. **Ontario Competency Questionnaire (OCQ)**
19. **Regional Capacity Assessment Team psychosocial tool (RCAT)**
20. **Structured Interview for Competency/Incompetency Assessment Testing and Ranking Inventory (SICIATRI)**
21. **The Silberfeld Questionnaire**
22. **Two-Part Consent Form**
23. Vignette methods (per Schmand)
24. Vignette method (per Vellinga)

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