

# Decision-making incapacity at the end of life: conceptual and ethical challenges

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## Abstract

A phase of decision-making incapacity (DMI) often precedes the end of life. DMI has important implications for a patient's involvement in treatment decisions. Although preferences expressed before a patient becomes decisionally incapacitated can still be taken into consideration, these are more binding if defined by an advance directive or a designated surrogate decision-maker. When a patient's preferences are not known, clinical decisions should be made according to what is believed to be in the best interest of the patient.

To date, there is neither a consensus on the concept of decision-making capacity (DMC) nor a clinical standard for its assessment (criteria, instruments, procedures). Since patient autonomy is widely regarded as a central value and with respect for patients' rights being seen as essential in modern health care, transparent, well argued and clearly defined standards for the assessment of DMC are needed. However, finding appropriate standards for DMC is a conceptual and ethical challenge.

**Key words:** decision-making capacity, competence, end of life, autonomy, advance directive

*Treatment choices* including in particular

consent to treatment or to its discontinuation as well as refusal of treatment (e.g., [1]), and assisted suicide<sup>2</sup> (e.g., [1–3])

*Advance directives*<sup>3</sup> and/or designated surrogate decision-makers (e.g., [4–9])

Advance directives are one effective way for individuals who are still in possession of their DMC to specify in advance who should make health care decisions when the individual is no longer able to, and/or which values or preferences should guide these decisions. Advance directives do not apply as long as individuals are competent, only once they have lost their DMC.

*Three critical aspects of DMI* can be distinguished: (1) the identification of persons who are incapable, (2) the means for making incapacity assessments, and (3) the relationship between professionals, institutions, and the state in this process. Specific groups such as children or migrants with cultural and linguistic differences raise additional issues that render the assessment particularly complex.

## A common condition at the end of life

The end of life is often preceded by a phase of *decision-making incapacity (DMI)* or cognitive incompetence (German: Urteilsunfähigkeit; French: incapacité de discernement).<sup>1</sup> DMI is caused by a broad range of clinical conditions, such as Alzheimer's disease, delirium, organic amnesic syndromes, brain injury and disorders of consciousness such as coma, vegetative and minimally conscious states as well as psychiatric diseases such as schizophrenia or severe depression, or, lastly, by medically-induced or illness-induced impaired consciousness of critically unstable patients too ill to participate in decision-making.

At the end of life, the assessment of *decision-making capacity (DMC)* is especially important to ensure that persons are capable of understanding and making decisions with respect to the following domains:

## A conceptual brainteaser

The *definition of the concept* of DMI is not trivial. It is not completely clear which mental abilities have to be affected to which degree in order to diagnose DMI. A comprehensive understanding, particularly with regard to its application in clinical settings, requires a multidisciplinary approach and analysis, drawing from the perspectives of ethics and philosophy more generally, as well as psychology, medicine (especially neurology and psychiatry), and the law.

## Swiss civil code

DMC or competence is a legal term which is circumscribed in the Swiss civil code as follows (Art. 16 ZGB):

1 The terms «incapacity» and «incompetence» are often used interchangeably in the English literature, although «competence» is typically used in legal contexts and «capacity» is commonly used in clinical contexts.

2 For example, one particular issue related to assisted suicide is the assessment of DMC in patients who are «tired of living» or who intend to commit a «rational suicide» but have no diagnosis of severe depression.

3 From the beginning of 2013, advance directives are for the first time integrated into the adult protection law (Art. 370 ff. ZGB; German: Erwachsenenschutzrecht; French: loi de la protection de l'adulte).

«A person has the capacity to consent within the meaning of the law if he or she does not lack the ability to act rationally by virtue of being under age or because of mental illness, mental incapacity, inebriation or similar circumstances.»<sup>4</sup> In the absence of these conditions, the law presumes that a person is competent and able to act reasonably.<sup>5</sup> According to Petermann [10], the ability to make reasonable decisions consists of two elements: First, to have *rational insights* regarding the consequences of one's own actions (German: *Erkenntnisfähigkeit*; French: *capacité de compréhension*) and second, to have the ability to *behave according to these insights*, that is to turn a decision into an *action* (German: *Steuerungsfähigkeit*; French: *capacité de se comporter selon ses compréhensions*). However, this general legal framework does not specify which concrete criteria have to be met in order to declare an individual competent or incompetent regarding a certain matter. Although this ambiguity has been articulated, e.g. in the recent debate on assisted suicide [10], the issue cannot be considered resolved in the Swiss legislative discourse.

### U.S. criteria

The following *criteria for medical decision-making capacity* are typically used in the U.S. (e.g., [12]): (1) ability to *understand* the relevant information, (2) ability to *appreciate* the medical consequences of the situation, (3) ability to *reason about* the treatment choices, and (4) ability to *communicate* a choice.

### Criteria of the Swiss Academy of Medical Sciences

The SAMS comes close to these criteria in their guidelines on the care of patients in the end of life [11]: (1) the ability to understand information regarding the decision that is to be made; (2) the ability to correctly weigh up the situation and the consequences resulting from possible alternatives; (3) the ability to weigh up, rationally, information obtained in the context of a coherent system of evaluation; and (4) the ability to express one's own choice.

The way the SAMS criteria 2 and 3 are phrased, they seem, however, more demanding than the U.S. criteria. That may be especially true for criterion 3, which demands a coherent system of evaluation.

### Threshold concept and relativity

DMC can be conceptualised as if each person's ability to make a decision is theoretically located at a point on a gradient or continuum between the two poles of DMC and DMI. The law, however, does not allow for a gradation or varying degrees of DMC but has a bivalent character (all-or-nothing, yes-or-no, capacitated or incapacitated), perhaps as a practical matter of efficiency for decision-making (*threshold concept* according to Buchanan and Brock [13–14]). Nevertheless, the law is able to handle relativity of DMC (*assumption of relativity* according to Buchanan and Brock [13]) by relating capacity to a specific concrete situation or action at a given point in time (e.g., [15]). For example, a person may have the capacity to make decisions about everyday life (where to live, what to buy, etc.) but may not be sufficiently capable of making decisions about health care when one's quality of life or even life itself may be at stake. In addition, once DMI has been declared, a person may not remain incapable for all future decisions; i.e., DMI may fluctuate. The threshold concept and relativity are the two central aspects of contemporary work on DMC which should be incorporated into law and clinical practice (according to the Stanford Encyclopedia of Philosophy [16]).

### An exclusively cognitive concept?

The above mentioned definitions operationalise DMC and DMI predominantly in terms of *cognitive and intellectual abilities*. Most studies assessing DMC used the Mini-Mental State Examination (MMSE [17]), which focuses on orientation, attention, and memory. Sessums, McCarthy, and Jackson [18] summarised 35 such studies and, not surprisingly, concluded that there is a strong relationship between DMC scores and cognition. The strong emphasis on cognition was criticised by several authors, among them Charland [19], Breden and Vollmann [20], and Welie [21]. These contributions claim that decisions are based to a large extent on *emotions, personal values, or intuitive factors*, which are not always accessible to a person's consciousness. If these factors are not attended to in evaluating decision-making, the *authenticity of a decision* stands in question (e.g., [22]).

### When is decision-making capacity doubted?

DMC is typically challenged when it seems that persons do not understand given information because of disorientation, difficulties with attention, concentration, or short-term memory (e.g., mental disability, dementia like Alzheimer's disease or organic brain syndrome). Also, DMC is doubted when persons behave as though the situation is not relevant to them, when they cannot

4 Official English translation of Art. 16 Swiss civil code as provided by the Classified Compilation of Federal Legislation: <http://www.admin.ch/ch/e/rs/c210.html>

5 The terms «ability to act rationally» and «ability to act reasonably» are often used interchangeably in the literature.

communicate their decision, and when they are in conflict, ambivalent or blocked (e.g., psychosis, catatonic stupor, severe depression or manic state). Furthermore, DMC is questioned when persons cannot apply relevant information to a specific decision (e.g., delusions, hallucinations, or illusions) or when persons have no insight regarding the nature of their disorder or their actual situation respectively (e.g., schizophrenia or Alzheimer's disease). Cases when DMC is doubted may also depend on clinicians' personal bias: For instance, whereas one clinician might have a particularly respectful attitude towards religion, carefully avoiding any association of religious beliefs with DMI, another might be rather critical of what he considers irrational religious beliefs and be less hesitant to diagnose DMI.

### How common is decision-making incapacity?

According to a large systematic review of 43 original studies by Sessums, McCarthy, and Jackson [18], DMI regarding consent to medical treatment is often not recognised by physicians (recognition of incapacity was examined in 8 of the studies). The authors state that «physicians missed the diagnosis in 58% of patients judged incapable, although when physicians do declare incapacity, they are usually right» (p. 425).

The prevalence of persons with DMI varies across different populations. Sessums, McCarthy, and Jackson [18] integrated data from 25 different studies assessing *capacity for treatment decisions* and came to the following *prevalence estimations* for DMI (p. 422; confidence interval and number of studies in brackets):

Healthy elderly control subjects	2.8%	(1.7–3.9%)	(n=16)
Mild cognitive impairment	20%	(14–26%)	(n=1)
Glioma patients	23%	(6.9–39%)	(n=1)
Medicine inpatients	26%	(18–35%)	(n=8)
Parkinson's disease	42%	(23–60%)	(n=4)
Nursing home	44%	(28–60%)	(n=5)
Alzheimer's disease	54%	(28–79%)	(n=10)
Learning disabled	68%	(41–97%)	(n=4)

Grisso and Appelbaum [23–24] have shown in a large study of several hundred participants that patients with internal medical problems, patients with psychiatric diagnoses, and even healthy controls may be incapable of making valid treatment decisions. Within the diagnostic groups the authors found big differences regarding medical DMI:

schizophrenia	52%
depression	24%
angina pectoris	12%
healthy control group	4%

Apart from psychiatric diagnoses, these data point to a significant minority of hospitalised patients who may be temporarily or permanently incapacitated as a feature of their illness and/or its medical treatment.

Studies have shown that between 3 and 25% of psychiatric consultations in general hospitals involved questions concerning capacity for making treatment-related decisions (e.g., [25]). Appelbaum [26] states that «any diagnosis or treatment that compromises mentation may be associated with incompetence» (p. 1835).

However, DMI cannot be directly inferred from psychiatric diagnoses, although several mental disorders are often linked with DMI (e.g. schizophrenia). Nevertheless, studies have shown that the majority of mentally ill patients are capable of making treatment-related decisions [27]. Patients with *dementia* show rather high rates of incapacity regarding both consent to treatment and consent to participate in clinical research. Kim, Karlawish, and Caine [28] have shown for example that more than half of persons with mild to moderate dementia show DMI and that incapacity is common among persons with severe dementia.

### Which is the appropriate assessment method?

How DMI is assessed influences the result of the assessment. For example, the ability to understand relevant information requires that the medical condition be explained to the patient in common language, without technical terminology [27]. Moreover, the assessor's attitude towards a critical issue (such as assisted suicide) or a conflict of interest (e.g. when assessing potential participants in a clinical trial) is likely to influence the outcome of the assessment. The outcome may also be biased if the context of the assessment is such that the patient is not able to make his or her decision and to communicate the choice without feeling threatened, under duress or external pressure [29]. While some variability may be unavoidable in borderline cases, variation due to vague definitions, poorly defined clinical criteria and unreliable, non-standard modes of assessment could and should be substantially decreased. An important distinction in the method of assessment can be made between (a) *clinical assessment* and (b) *use of standardised assessment tools*. In clinical practice, psychiatrists or general practitioners often estimate DMC based on their personal clinical experience [30]. However, in the last two decades more and more standardised assessment tools have been developed, in part, to reduce the risk of bias introduced by the assessing individuals (for overviews see [18, 21, 31]). Several frequently used tools are listed below (for an extended list of more than 20 tools, see [18]):

- Mac Arthur Competence Assessment Tool (MacCAT-T [12]; German version [32])
- Aid to Capacity Evaluation (ACE [33])
- Hopkins Competency Assessment Tool (HCAT [34])
- Silberfeld's competence tool [35]
- Capacity to Consent to Treatment Instrument (CCTI [30])
- Tur-Mental-Competency-Test (according to [10])

These assessment tools differ with respect to their levels of scientifically supported evidence, i.e. the quality and quantity of validation studies. With regard to the applied validation methods, the assessment tools are somewhat heterogeneous. Some of the tools were compared to a gold standard (*criterion validity*) which was mostly defined as a clinical assessment of the DMC by expert psychiatrists or multidisciplinary expert panels (see [18]). Despite the heterogeneity of methods for establishing validity and reliability, the ethical responsibility remains for insuring that clinicians are accurately and fairly measuring DMC and that similar patients are evaluated similarly.<sup>6</sup>

### The attribution of decision-making incapacity always contains a value judgment

One especially disturbing finding is that theoretically well-founded and methodically sophisticated assessments paradoxically show higher proportions of patients with DMI [36]. This legitimates particular investigation with attention to protecting patients' rights to make their own decisions whenever possible. It appears likely that overly demanding standards for assessing DMC may be masking medical paternalism, as Schöne-Seifert [37] pointed out. As these data make clear, the attribution of DMI does not rest solely upon an *empirical test* (descriptive level), but always contains a *value judgment* (normative level).

### State of the research and what is needed

In summary, the literature so far comprises mainly three types of studies:

(1) ethical and legal discussions of appropriate criteria for DMI, reflecting the tension between a public duty to respect the rights of those who are able to make their own decisions on the one hand and, on the other, to provide protection for incapable decision-makers and decisions; (2) the presentation of tools for the assessment of DMI; and (3) empirical studies of the prevalence of DMI in the context of certain diseases.

What is lacking are surveys and qualitative work on the problems clinicians face when applying either criteria or instruments to individual cases. Another area in need of further attention is discrepancy in existing standards for DMI. How to calibrate necessary protection against inappropriate protectionism, and how to respond to the nuances of individual clinical cases, are questions that need to be tackled in multidisciplinary exchanges among ethicists, lawyers, psychologists and clinicians. As any solution will always refer to current

social norms regarding what kind of protection we owe to whom, standards need to be revisited and possibly adapted to the context in question. Switzerland would certainly profit from a well-argued, evidence-based contribution to this process.

Defining and assessing DMC in an appropriate way is of significant concern, particularly with a view to current demographic trends, anticipating a larger prevalence of patients with dementia, a major cause of DMI. Moreover, a well-designed assessment process may increase efficiency in clinical settings. The determination of DMC needs to protect patients' right to self-determination, and at the same time provide adequate protection for those who are not able to decide for themselves at a given moment.

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## Zusammenfassung

### Urteilsunfähigkeit am Lebensende: Konzeptionelle und ethische Herausforderungen

Das Lebensende ist oftmals mit einer Phase der Urteilsunfähigkeit verbunden, die wichtige Konsequenzen für den Einbezug eines Patienten in Behandlungsentscheidungen hat. Auch wenn Präferenzen, die ein Patient vor seiner Urteilsunfähigkeit geäussert hat, mit einbezogen werden können, sind diese verbindlicher, wenn sie zuvor in einer Patientenverfügung festgelegt wurden oder eine Vertretungsperson ernannt wurde. Sind die Präferenzen eines Patienten unbekannt, sollten klinische Entscheidungen sich am mutmasslich besten Interesse der Betroffenen orientieren.

Bislang besteht weder ein Konsens hinsichtlich des Konzepts von Urteilsunfähigkeit noch ein klinischer Standard zu dessen Überprüfung (Kriterien, Instrumente, Prozeduren). Aufgrund der starken Betonung der Patientenautonomie und der Tatsache, dass Patientenrechte als unverzichtbarer Bestandteil einer modernen Gesundheitsversorgung angesehen werden, sind transparente, gut begründete und klar definierte Standards für die Feststellung der Urteilsunfähigkeit von Patienten notwendig. Diese festzulegen, bringt eine Reihe von konzeptionellen und ethischen Herausforderungen mit sich.

<sup>6</sup> The practical usefulness of these assessment tools and their integration in the overall clinical assessment process is controversial. The topic is the subject of the ongoing research work carried out by the authors.



## Résumé

### L'incapacité de discernement en fin de vie: défis conceptuels et éthiques

La fin de vie est souvent marquée par une incapacité des patients à prendre des décisions concernant le choix et l'application d'un traitement. Les préférences formulées antérieurement sont plus contraignantes lorsqu'elles sont consignées dans une directive anticipée ou rapportées par une personne désignée à cet effet. Lorsque les préférences d'un patient ne sont pas connues, les décisions médicales doivent être adoptées en fonction de l'intérêt supposé.

Il n'existe ni consensus sur la notion de capacité de discernement, ni standards cliniques permettant de contrôler cette capacité (critères, instruments, procédures). Des standards transparents, justifiés et clairs sont – au regard du principe d'autodétermination des patients et de la reconnaissance de leurs droits comme élément intrinsèque des systèmes modernes de soins – nécessaires pour s'assurer de la capacité de discernement des patients. La définition de ces standards est un défi à la fois conceptuel et éthique.

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