MEDICAL ETHICAL GUIDE-LINES

Assessment of capacity in medical practice

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Medical-ethical guidelines

Assessment of capacity in medical practice

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The German text is the authentic version.

The Swiss Professional Association for Nurses (SBK/ASI) recommends that its members and all other nurses should abide by these guidelines.

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I. PREAMBLE

Capacity is of fundamental importance in everyday medical practice. Only patients with capacity can legally consent to medical treatment or express their wishes in an advance directive. If patients lack capacity and their wishes have not been specified in advance, their role in decision-making is assumed by surrogates. The presence of capacity is thus a key factor marking the distinction between autonomy and heteronomy.[1]

Although capacity is generally assumed to be present,[2] an assessment of capacity may be indicated if reasonable doubts arise. Such an assessment is a highly delicate matter. Denying a person the right to decide on personal questions such as consent to medical treatment is a serious intervention, which can have major impacts on the individual's self conception, on relations between the patient and the care team, and on the patient's other relationships. From an ethical perspective, an intervention of this kind is only justifiable if the basis for autonomous action is lacking and the person concerned needs to be protected against possible adverse consequences of his or her own decisions.

Capacity is not a medical, but a legally defined concept.[3] A yes-or-no judgement is required – the patient either has or does not have capacity in relation to a given decision. In medical practice, however, the assessment of capacity is not always so straightforward. What needs to be evaluated are abilities which only develop with age, or which may be temporarily or permanently impaired as a result of disease or other factors.

Not just the patient's capacity but also the clinician's ability to assess it may be impaired: bias – e.g. due to strongly held ideological convictions, individual values or personal conflicts of interest – can lead to a distorted evaluation. To ensure high-quality assessment, appropriate management of partiality is essential, since the results can have far-reaching consequences for the patient. Denial of capacity must not be arbitrary: the decision must be based on transparent criteria and be intersubjectively comprehensible.

Studies indicate that physicians, nurses and other health professionals are often uncertain and desire additional guidance in the assessment of capacity.[4] Numerous guidelines and other clinical aids make reference to capacity without, however, further operationalising this concept.

1 Surrogate decision-makers are, however, required to be guided in all cases by the expressed or presumed wishes of the person concerned.
2 Except in cases of obvious *in*capacity, e.g. in infants or in unconscious patients.
3 According to Art. 16 of the Swiss Civil Code, a person has mental capacity if he or she «does not lack the ability to act rationally on account of minority, or as a result of a mental disability, a mental disorder, intoxication or similar conditions». For further information, see the Annex, Section 1. «Legal foundations».
4 Cf. Lamont et al. 2013, Hermann et al. 2014.

The present guidelines thus offer guidance for medical practice. They define the principles to be observed in the assessment of capacity and describe the procedure to be adopted, both in general and in particular areas of medical practice. The legal foundations, as well as tools for capacity assessment, are described in the Annex.

II. GUIDELINES

1. Scope

These guidelines focus on the assessment of capacity in a medical context.[5]

The guidelines refer to Swiss legislation, specifically to Article 16 and the child and adult protection provisions of the Swiss Civil Code (SCC). They are addressed to physicians[6] and other health professionals concerned with the assessment of patients' capacity in everyday clinical practice. The health professional who, in line with his or her authority, is responsible for the assessment procedure and for the results thereof should seek interprofessional exchanges within the team and may call in additional expertise.

The guidelines do not define standards for expert assessments of mental abilities or conditions, e.g. via neurological, psychiatric or psychological expert opinions.

2. Principles

2.1. Capacity is generally assumed to be present

A person is generally deemed to have capacity. Capacity is only systematically assessed in cases where reasonable doubts arise as to its presence, or where an assessment is legally required.[7] The patient is to be informed about the assessment. In general, *in*capacity cannot be automatically assumed on the basis of age or of a particular diagnosis.

2.2. *In*capacity is ascribed on the basis of ethical/normative considerations

*In*capacity is not an inherent property, but is ascribed to a patient on the basis of the weighing of relevant information, taking into consideration the moral principles of respect for autonomy and beneficence. The ascription is thus based on ethical/normative considerations as to whether the patient should be denied responsibility for decision-making.

5 The expression «medical context» covers all actions and decisions relating to medical treatment and care. This also includes participation in a medical research project.

6 SAMS guidelines are addressed to health professionals (physicians, nurses and therapists). On being incorporated into the Code of the Swiss Medical Association (FMH), SAMS guidelines become binding for all members of the FMH.

7 Cf. Annex, Section 1. «Legal foundations».

2.3. *In*capacity is ascribed in a situation- and time-specific manner

*In*capacity is only ascribed to a patient in relation to a specific decision and at a particular point in time. This specific ascription must not be regarded as permanent; rather, capacity is to be reassessed if there is evidence that the patient's condition has changed.

2.4. Capacity requires certain mental abilities

Not only cognitive but also emotional, motivational and volitional (i.e. relating to the making and communication of decisions) factors are relevant to the patient's capacity, which involves the following categories of mental abilities:

- Cognitive ability: the ability to grasp at least the fundamental elements of the information relevant for the decision;
- Evaluative ability: the ability to assign a personal meaning to the decision situation, in the light of the various options available;
- Decisional ability: the ability to make a decision on the basis of the information available and one's own experience, motives and values;
- Expressive ability: the ability to communicate and defend this decision.

The more complex the decision, the greater the demands placed on the mental abilities. Appropriate assessment of these abilities calls for a holistic view of the person concerned.

2.5. *In*capacity can only be ascribed in cases where mental abilities are significantly impaired

For *in*capacity to be ascribed, there must be a significant impairment of mental abilities. In addition, the impairment must be attributable to a cause falling under the legal categories of «minority», «mental disorder», «mental disability», «intoxication» or «similar conditions».

2.6. *In*capacity must not be ascribed merely on the basis of unexpected decisions

In the assessment of capacity, value pluralism, different cultural contexts and unconventional thinking are to be respected. It is not permissible to ascribe *in*capacity merely because a patient makes a decision which is at odds with the recommendations and perspective of the person conducting the assessment. The content of or motives for decisions may, however, give rise to reasonable doubts and thus prompt a more detailed assessment.

2.7. The patient's mental abilities are to be supported and promoted

Wherever possible, autonomous decision-making and the requisite mental abilities in the patient are to be supported and promoted by appropriate interventions. Obstacles should be eliminated as far as possible, and the patient's resources identified and mobilised.

2.8. The significance of the decision is relevant for the assessment

The more far-reaching or long-lasting the consequences of a decision, the more carefully should it be determined whether *in*capacity is present. This is particularly true in the case of options with consequences which are irreversible or will even, in all likelihood, be fatal. If any doubts arise, or for decisions of major significance, it is recommended that capacity be assessed, if appropriate, in an interdisciplinary, interprofessional manner, drawing on special expertise.

2.9. The ascription of *in*capacity is to be appropriately justified and documented

The ascription of *in*capacity is to be justified by the person conducting the assessment. In the justification, the impairments leading to the ascription must be clearly indicated. Consideration and critical reflection should also be given to objections and opposing positions. The results of the assessment and the underlying arguments are to be appropriately documented and made available to the patient, or the patient's representative, on request. If the patient does not agree with the results of the assessment, he or she may request that additional expertise be called in, or seek a second opinion.

2.10. Reflection is required on social and personal values and norms, and conflicts of interest

The ascription of *in*capacity is influenced by social and personal values and norms of the person conducting the assessment. In addition, conflicts of interest involving this person may exert an influence. Any such influences require critical reflection and transparency. In the event of substantial partiality arising from personal values or conflicts of interest, the person concerned should not conduct the assessment.

3. Areas of practice

3.1. General

Medical interventions require the consent of the (competent) patient concerned.[8] Capacity is generally assumed to be present. If doubts arise in this regard, an initial investigation and, if appropriate, a more detailed assessment is to be undertaken.

The initial investigation generally involves a more or less informal process, the results of which are frequently not documented (in detail) and are not usually discussed with the patient. A health professional who concludes, on the basis of such an initial investigation, that a more detailed assessment of capacity is required must inform the patient accordingly. This discussion should be open and honest, taking the patient's mental and emotional condition into consideration. If the patient rejects and/or refuses to participate in such an assessment, a clinical assessment of capacity must be undertaken on the basis of the information available, which then serves as the basis for subsequent steps (e.g. involvement of the authorised representative[9] or, in the absence thereof, the Child and Adult Protection Authority, CAPA).

Concerns about cognitive abilities are often raised by persons who are closely related to a patient or involved in the patient's care. Such concerns must be evaluated critically, particularly with regard to possible conflicts of interest. A detailed assessment of capacity is only indicated if reasonable doubts arise in this regard and the presence or absence of capacity would have an influence on subsequent steps.

Capacity cannot be determined by simple tests. Rather, it is assessed within the framework of a clinical evaluation, frequently with the aid of tools such as lists of criteria and interview guides.[10] The health professional conducting a detailed assessment of capacity should have the appropriate knowledge and skills. High-quality assessment and careful documentation are essential. The latter enables the patient to comprehend and, if appropriate, object to the procedure. As far as possible, the therapeutic relationship should not be disturbed by the assessment of capacity.

8 This does not apply to urgent situations where, in the interests of preserving life, immediate action is required and it is not possible for a detailed assessment of capacity to be carried out in advance.

9 With regard to medical interventions, the following persons, in the following order, are entitled to act as representatives for the person lacking capacity: (1) persons appointed in an advance directive or power of attorney; (2) a duly authorised deputy; (3) a spouse or registered partner who shares the same household *or* regularly provides personal support for the person lacking capacity; (4) the person who shares the same household as *and* regularly provides personal support for the person lacking capacity; (5) the offspring, (6) the parents or (7) the siblings, *if* they regularly provide personal support for the person lacking capacity (Art. 378 SCC). For patients receiving medical treatment in connection with an involuntary committal, Art. 434 SCC is applicable.

10 Cf. Annex, Section 2. «Assessement of capacity».

The approach adopted should ensure that the patient's capacity for self-determination is supported as effectively as possible. The goal of the assessment is to ensure that the decision-making procedure for medical interventions corresponds to the patient's abilities and as far as possible reflects the patient's needs and preferences. Regardless of whether or not the patient currently has capacity, the course to be pursued will be determined by his or her wishes. The only question is whether the patient's current assertions can be interpreted as wishes or whether, instead, an advance directive or surrogacy arrangements should come into effect. Here, it should be borne in mind that patients may take the effects of a decision on their relatives into consideration and – out of loyalty or because of disease-related changes in values (e.g. in depression) – disregard their own interests. At the same time, patients are entitled to take their relatives' interests into account and to set their own needs aside. Ambivalence may be discernible in a patient who makes contradictory statements or is unable to make a decision. Such ambivalence must not, however, be automatically equated with *in*capacity. If there is evidence of such behaviour, the care team must make sure that the decision reflects the patient's wishes and is not attributable to the unconscious or deliberate exertion of pressure by relatives.

The content, duration and scope of capacity assessment discussions should be adapted to the patient's physical, cognitive and emotional abilities. The assessment can be supported by the presence of persons close to the patient – should he or she so desire. They know the patient best and are often best able to judge which assertions reflect their relative's wishes. Patients must, however, always be given an opportunity to express their views without third parties being present. In situations which are complex or marked by conflict, an external (psychiatric, neuropsychological, memory clinic) consultation can be helpful, also in protecting the existing therapeutic relationship.

In the assessment, the following constituent abilities are systematically examined, although the examination may focus on one particular area, depending on the patient's situation (cf. Section 2.2. ff.):
- cognitive ability;
- evaluative ability;
- decisional ability and
- expressive ability.

The procedure can be supported by assessment and documentation tools.[11] The results of the assessment are to be noted in the patient's records and communicated to the patient in an appropriate form. The patient and, if appropriate, the authorised representative can inspect and comment on the documentation. He or she can propose amendments, seek a second opinion and, if necessary, consult the CAPA.

11 Cf. Annex, Section 2. «Assessement of capacity».

3.2. Patients in general practice

Given the wide range of patients seen in general practice, an assessment of capacity will be required in a variety of situations – mainly for (very) elderly patients, but also for adolescents and for patients with chronic conditions, mental disabilities, addiction problems or mental disorders.

Often, general practitioners have known patients for a long time, obtain relevant information from people close to them (e.g. relatives, home care providers), and in many cases are also familiar with their living environment. In long-standing patients, any cognitive problems can therefore be observed over an extended period, and the patient's condition can be periodically examined and documented. Ageing processes do not in themselves give rise to *in*capacity, unless marked disorders of brain function are present. Frequently, the GP is well placed to evaluate capacity in relation to a decision which needs to be made. If the existing relationship, a patient-oriented approach and mutual trust enable shared, consensual decision-making, adapted to the patient's cognitive abilities, then an assessment of capacity can often be dispensed with for medical decisions in the general practice setting.

However, in the case of decisions of major importance, and if there is evidence of significantly impaired mental abilities, a detailed assessment of capacity is required – also to ensure that an advance directive (if available) can be taken into consideration or authorised representatives can be involved in decision-making.

3.3. Children and adolescents

Questions concerning capacity regularly arise in paediatrics and adolescent medicine. For the presumption of capacity, there is no legally defined minimum age, nor is there any dependence on majority.[12] The abilities relevant for capacity develop at different rates from early childhood to adulthood. In children and adolescents, mental abilities are influenced not only by the individual developmental stage, but also by life experience. The age at which capacity is attained for a particular medical decision depends not just on personal factors but also to a great extent on the complexity of the question and how close it is to (or far removed from) the child's life-world and life experience. The assessment of capacity in children and adolescents requires expertise in developmental psychology. Even where capacity is lacking, it should be ensured that the child is involved in the decision-making process and that the child's wishes are also taken into account.

Medical information must be adapted to the developmental stage of the child or adolescent. Here, it should be borne in mind that children and adolescents often have difficulty in estimating and evaluating the effects of decisions on their future life. If they focus on the «here and now», this can influence their insight

12 For further information, cf. Annex, Section 1. «Legal foundations».

into their condition and the need for treatment, with the significance and practical consequences of decisions not being adequately recognised and appreciated (cognitive ability, evaluative ability).

Tensions may exist between the values of the child or adolescent and the ideas of the parents, concerned about their offspring's welfare. The situation is further complicated if the parents disagree among themselves, or if their conception of the child's welfare differs significantly from that of the care team. Children and adolescents have the right to decide for themselves on medical treatments with regard to which they have capacity. The parents are, however, responsible for their support and upbringing and may therefore reasonably expect to be involved in the information process. This conflicts with the duty of medical confidentiality, which is also applicable vis-à-vis the parents of adolescents with capacity (e.g. for prescription of a contraceptive). In such situations, the assessment of capacity plays a crucial role with regard to the question to what extent parents should be informed and involved in health related decision-making. Although, when capacity is attained, the right to decide on medical interventions passes from the parents to the adolescent, decision-making processes both before this point and for a long time thereafter frequently involve a complex interaction between the parents and the child, or adolescent, which is often not perceptible to the treatment team. Ideally, parents will grant a child that does not yet have capacity as much of a say in decision-making as possible, and adolescents with capacity will grant their parents an advisory or joint role in decision-making in cases where they feel unable to decide by themselves.

In the case of particularly burdensome and high-risk interventions, even if the parents and child or adolescent have jointly consented, it should be carefully examined whether the child or adolescent's consent has been granted in a truly autonomous manner. In situations involving a risk of serious harm or death, young patients may – deliberately or not – be placed under pressure by their parents to consent to or refuse a treatment (decisional ability, expressive ability). It is therefore important also to speak to the child or adolescent without the parents being present. Particular challenges arise in connection with problems such as suicidality, gynaecological matters, eating disorders or treatment compliance in chronic illness. In difficult situations, an assessment by a child psychiatrist and/or the involvement of the CAPA may be appropriate.

3.4. Patients with mental disabilities

Patients in whom the development of cognitive abilities and hence mental capacity is impaired from childhood, as a result of congenital or acquired disorders, pose a particular challenge for the assessment of capacity. Even if they are subject to a general deputyship, on no account should they be automatically assumed to lack capacity. With suitably adapted information, empathetic communication and adequate investment of time, autonomous decisions are possible on numerous med-

ical matters, in spite of initial appearances to the contrary. However, this requires appropriate experience and communicative skills.13 Relatives and/or caregivers can be helpful in this process. In cases of *in*capacity, surrogacy arrangements are to be observed (deputyship exercised by relatives, professional deputyship or, in the absence of a deputyship, the arrangements for representation in medical matters specified in the SCC). In such cases, the patient also has a right of participation.

3.5. Patients in emergency and intensive care

In emergency care, patients' *in*capacity due to altered consciousness or cognitive impairments may be evident and already be determined on the basis of the case history or clinical examination. Also common are clinical conditions associated with serious cognitive impairments and potential *in*capacity (e.g. encephalopathy, delirium or intoxication). A detailed assessment of capacity is appropriate in these patients.

In an emergency situation, measures to increase the chances of survival, reduce sequelae and alleviate symptoms are given priority, and there is generally no time for an assessment of capacity. In the absence of known wishes to the contrary, the care team assumes that treatment is desired by the patient.[14]

As soon as the patient's condition has stabilised, capacity must be assessed if there are any doubts in this regard. If the patient refuses a proposed treatment, the team must consider the possibility that the refusal may be a symptom of the underlying disorder, a consequence of delirium, or an expression of anxiety or inability to cope. In such circumstances, particular importance attaches to the ability to assign a personal and appropriate meaning to the decision situation (evaluative ability).

In emergency and intensive care situations, the assessment is complicated by various factors. Often, time is short and decisions have to be taken rapidly. In many cases, it is not possible to provide detailed information or to give the patient the time required to consider various treatment options in depth and possibly also seek the advice of third parties. In addition, the physician usually does not know the patient and therefore cannot use an existing therapeutic relationship as a basis for interpreting the patient's needs and placing them in a broader context.

In an acute situation, there may also be cases where patients who request immediate relief of symptoms thereby agree to a treatment that is not in accordance with their previously expressed wishes. The care team must take into account the fact that capacity can be impaired by physical symptoms. Treatment options should therefore be discussed primarily when patients are clinically stable and relatively free of symptoms; the initial treatment decision should then also be re-examined.

13 Cf. SAMS medical-ethical guidelines «Medical treatment and care of people with disabilities» (2008, updated 2013).
14 Cf. Art. 379 and Art. 435 SCC.

In patients with chronic conditions where acute deteriorations and complications are to be expected, the state of capacity – while it remains intact – should be used to discuss treatment options in advance and, if appropriate, to specify preferences within the framework of advance care planning.

Certain treatments influence cognitive or communicative abilities (e.g. sedatives, other psychotropic drugs, intubation). If such treatments are employed, the care team must not automatically assume that the patient lacks capacity as a result. Rather, it must assess the patient's capacity for each decision subsequently required. For this purpose, the best possible conditions should be established. This can be achieved by means of communication adapted to the situation, the elimination or reduction of disruptive factors, and the involvement of relatives to provide support.

3.6. Patients with mental disorders

The assessment of capacity in patients with mental disorders is guided by the same principles as apply for all other patients in medicine. Capacity is generally assumed to be present, and a detailed assessment is only indicated if reasonable doubts arise in this regard.

In general, the majority of patients with mental disorders have capacity in relation to treatment decisions.[15] Within diagnostic groups, however, there is considerable heterogeneity with regard to the mental abilities relevant for autonomous decision-making. In the various diagnostic groups, there may be both persons whose capacity is intact and others whose capacity is impaired in relation to particular decisions (e.g. consenting to indicated treatment) at a particular time.

Depending on the type of mental disorder, different mental abilities relevant for autonomous decision-making may be impaired for a more or less extended period. For example, in affective (e.g. depressive or bipolar) disorders, emotional or motivational factors are typically affected (evaluative ability), while in schizophrenia and psychotic disorders cognitive abilities tend to be impaired and the sense of reality may be disturbed. In delusional disorders and other disorders of content of thought, the assessment of capacity poses particular difficulties as a result of a possibly disturbed sense of reality or the possible presence of unshakeable false beliefs due to pathological processes (cognitive ability).[16]

The values- and situation-specific assessment of capacity is a demanding task. In particular, capacity must not be called into question solely on account of the patient's refusal of treatment.

15 Cf. Okai et al. 2007.
16 Cf. Appelbaum & Grisso 1988.

The patient should be informed about the performance and the results of the detailed assessment of capacity, so that he or she has an opportunity to contest a judgement considered to be unjustified. It should be noted that, from a legal viewpoint, *in*capacity is not a requirement for involuntary committal[17] under Art. 426 ff. SCC. The decisive factor is the presence of a serious risk of harm to the patient which cannot otherwise be averted.[18] In contrast, the ordering of treatment without consent, by the chief physician, in involuntarily committed patients under Art. 434 SCC is only permissible if the patient concerned lacks capacity in relation to the specific need for treatment.[19]

3.7. Patients with dementia[20] and other disorders of brain function

Disorders of brain function – progressive or stable, acquired or congenital – are usually manifested in cognitive impairments (attention, learning and memory, language, perception, planning abilities, etc.) and/or in behavioural disturbances (including a risk of harm to the patient or third parties).

Information about cognitive or behavioural problems may be provided by patients themselves or by relatives, but symptoms may also be observed by the attending physician, suggesting the need to assess capacity. With disorders of brain function, the presumption of capacity is also applicable. Assessments must be performed in a situation- and time-specific manner. People with moderate dementia may, for example, still have capacity in relation to simple interventions and care measures, dietary preferences, etc. However, even when such wishes are evaluated, the patient's perceptions – and, in particular, insight into the condition – must be taken into consideration in the assessment of capacity. While capacity may be retained in relation to simple measures, it is frequently lacking for more complex decisions. Even with regard to the desire to remain in a familiar environment, the assessment of capacity is often not easy. Only with more serious conditions (e.g. severe dementia) can the patient be assumed to lack capacity.

In patients with disorders of brain function, the assessment of capacity may be complicated by impairments of attention, memory, perception and verbal capacity. Decision-making ability can be promoted by the use of short, simple sentences and the elimination of distracting environmental factors, etc. It is advisable to

17 This also applies to the detention of patients admitted voluntarily under Art. 427 SCC.
18 A prerequisite for the ordering of involuntary committal is the existence of a debilitating condition (mental disorder or disability, or severe neglect) necessitating treatment or care which cannot be provided other than through involuntary committal to an appropriate institution (individual need for protection). An unreasonable burden placed on relatives or other third parties may be an additional important criterion, but it cannot in itself justify the ordering of involuntary committal.
19 For more details, cf. the SAMS medical-ethical guidelines «Coercive measures in medicine» (2015).
20 For the definition of dementia, cf. the SAMS medical-ethical guidelines «Care and treatment of people with dementia» (2017), Section 2 (Definition and stages of dementia).

repeat crucial questions several times in different ways, so as to be able to assess the consistency of responses (cognitive ability, decisional and expressive ability). Perception and communication should be facilitated (e.g. via hearing aids/spectacles), if the patient so desires.

People with dementia have a high risk of developing delirium (acute confusional state). In these situations, the underlying medical problem responsible for the cognitive fluctuations must first be treated before capacity is assessed. A review of medication or dosages may be helpful. Attention should also be paid to adequate nutrition and hydration, pain relief and a familiar environment.

3.8. Patients in palliative care

In palliative care, the assessment of capacity can be complicated by fluctuations in patients' ability to concentrate, to reflect and to express themselves. Such fluctuations can be caused by a (temporary) state of confusion, but also by the patient's susceptibility to fatigue. For this reason, it may be helpful to discuss certain situations in advance, when the patient's condition more readily permits discussions of this kind.

Relatives are sometimes very much on hand and closely involved in the patient's treatment. There is a risk of the care team paying insufficient attention to, or neglecting to ascertain, the patient's wishes and speaking to the relatives instead. In such cases, the care team has a tendency to act as if the patient lacked capacity, or at least full capacity. Such behaviour may be prompted by various factors: for instance, the desire to spare the patient – already debilitated – a difficult and tiring discussion; avoidance of effort, if it is quicker or easier to talk to the relatives (e.g. about a hopeless prognosis); but also the difficulty, for the care team, of going against the relatives' wishes. If the relatives are opposed to the patient being informed about his or her condition, or being involved in treatment planning, the care team should investigate the motives and reasons for their opposition. In addition, the patient's right to be informed and to make decisions autonomously should be explained.

Through patient-centred care, the care team can support the patient's autonomous decision-making, particularly if interactions with relatives are trusting and constructive. If appropriate, the medical care proposed should include the option of forgoing treatment. This requires that care team members be aware of their own values and attitudes with regard to serious illness and its consequences. If patients cannot or do not wish to summon up the energy to make a decision, this does not imply that they lack capacity. Patients may adopt and tacitly accept treatment recommendations made by other people. They have the right to change their mind at any time.

3.9. Assessment of capacity in patients desiring assisted suicide

Health professionals may sometimes be asked to certify capacity by a patient desiring assisted suicide. They must decide, on their own responsibility, whether performing this task is compatible with their individual conception of professional ethics and with their personal values.

Given the significance of the decision, particular care is to be exercised in assessing whether the patient's mental abilities are impaired as a result of mental illness[21] (e.g. depression) or some other factor. In this case, a detailed assessment must be performed to determine whether this gives rise to *in*capacity in relation to the desire for suicide. In particular, it should be established whether the patient has a realistic view of the prognosis and of the chances of success of the therapeutic and other support options available.

21 In 2006, the Federal Supreme Court ruled that, in the case of patients with mental illness, a detailed psychiatric opinion is required (BGE 133 I 58 E. 6.3.5.2).

1. Legal foundations

In Art. 16 of the Swiss Civil Code (SCC), capacity is defined as follows: «A person has mental capacity within the meaning of the law if he or she does not lack the ability to act rationally on account of minority, or as a result of a mental disability, a mental disorder, intoxication or similar conditions.»

Thus, what is defined by the law is not capacity in the positive sense, but the exceptions to it, i.e. *in*capacity. The double negation contained in this definition underlines capacity as the normal state. Accordingly, someone – e.g. a physician – who alleges that a person lacks capacity must generally also prove that this is the case (Art. 8 SCC). The standard of proof is the balance of probabilities.[22] The presumption of capacity is no longer applicable only if a patient's mental abilities are permanently, evidently and indisputably impaired; here, the person may be assumed to lack capacity in general.[23]

In certain situations, however, specific legal provisions call for a positive determination (sterilisation[24]) or explicit assessment of capacity (living organ donation[25]). The assessment is to be documented. Recommended by medical-ethical guidelines and by jurisprudence is particularly careful assessment and documentation of capacity with regard to assisted suicide and inclusion in a research project, if capacity is in doubt, as well as for medical treatment without consent in connection with involuntary committal under Art. 434 SCC.

Capacity is also a requirement whenever an advance directive is drawn up.[26] The question of capacity is of particular importance in this context because the individuals concerned are specifying in advance their wishes for a future time at which

22 Cf. Widmer Blum 2010.

23 Cf. ibid., citing the Supreme Court ruling BGer 5C.193/2004, E. 4.1.

24 Cf. Art. 5 of the Sterilisation Act: 1 The sterilisation of a person aged over 18 years may only be undertaken if the person concerned has been comprehensively informed about the procedure and has given voluntary consent in writing. 2 The person carrying out the procedure must specify in the medical records the observations on the basis of which capacity has been determined.

25 Cf. Art. 12 of the Transplantation Act: Organs, tissues and cells may be removed from a living person if: a. that person has capacity and has reached the age of majority (...); and Art. 10 of the Transplantation Ordinance: 1 Organs, tissues and cells may only be removed from a living person if it has been ascertained by an independent expert with experience in such assessments that donation is being undertaken on a voluntary and non-commercial basis. 2 The expert must document the assessment and retain the documentation separately from the medical records for ten years.

26 Cf. SAMS medical-ethical guidelines «Advance Directives» (2009, updated 2013), p. 7: «A person drawing up an advance directive must be in the position to understand the implications of the advance directive and must be able to estimate, as far as this is possible, what consequences it would have in the case of a certain pathological condition.» To be valid, an advance directive must be drawn up in writing and signed by the person concerned in a state of capacity. Advance directives must generally be implemented,
unless they contravene legal requirements or reasonable doubts arise as to their voluntariness or whether they (still) reflect the patient's presumed wishes.

they will no longer have capacity. The assessment of capacity to draw up an advance directive does not essentially differ from other situations in which a patient's capacity is assessed. Here, too, the person is generally assumed to have capacity, and an assessment is only carried out if this is desired by the person drawing up the advance directive (e.g. because dementia has been diagnosed) or if reasonable doubts arise as to his or her capacity. However, retrospective assessment is not always easy. Certification of capacity by a third party, obtained when the advance directive is drawn up, can be helpful in certain situations (e.g. if objections are raised by family members).

The legal definition of capacity in Art. 16 SCC not only includes *subjective elements, namely the ability to act rationally*, but also requires the *absence of objectively determinable physiological or mental factors* which can impair capacity.

According to legal doctrine and jurisprudence, the *subjective ability* to act rationally comprises two elements: firstly, the ability to reach a rational decision (*decisional ability*) and, secondly, the ability to act in accordance with this decision (*expressive ability*).[27] Decisional and expressive ability, in turn, require various constituent abilities, namely rational understanding and the ability to grasp reality on the basis of life experience and appreciate the practical significance of decisions, to establish and weigh up comprehensible motives, to control behaviour rationally, and to reach and execute decisions.

The *objective factors (minority, mental disorder and mental disability, intoxication or similar conditions*) referred to in the legislation are not valid in an absolute sense. For example, with regard to minority, no fixed age level can be assumed for capacity; children's development varies. In the literature, the following ages are given for rough guidance: for minor medical decisions a minimum age of 7 years is appropriate, 12 years is recommended for simple interventions and 16 years for complex or prolonged treatments. *Mental disorders* cover not only psychiatric conditions (e.g. psychosis, psychopathy) but also disorders such as dementia or addiction. *Mental disability* refers to congenital or accident-related cognitive impairments.

Capacity can, however, also be impaired by serious somatic diseases or severe shock. What is decisive in the case of these objective factors is not their presence, but the question whether and how – in a specific case – they affect abilities that are prerequisites of capacity. *Intoxication* refers to impairments (e.g. due to alcohol, drugs or medications) which can temporarily impair capacity. *Similar* covers other conditions (e.g. shock, delirium, etc.) which can impair capacity.

27 Cf. Bucher 1976, N 42 ff. on Art. 16 SCC, cited in Aebi-Müller 2014.

Capacity is not assessed in general terms, but always in relation to a specific expression of wishes and a particular decision. The person concerned must have capacity at the time the wishes are expressed and in relation to the particular matter to be decided (*temporal and material relativity of capacity*). The Supreme Court formulates this principle as follows: «It should also be noted that there is no provision for abstract determination of incapacity in Swiss law. Rather, the court has always to assess whether the person in question can be regarded as having capacity in a specific case, i.e. in connection with a certain action or in the appreciation of certain actual facts.»[28]

Temporal relativity means that the person concerned need only have capacity at the time his or her wishes are expressed. For example, certain forms of dementia (e.g. Lewy body dementia, vascular dementia) may be associated with marked cognitive fluctuations. For the assessment of capacity, a time and setting must be chosen which ensure that the patient feels comfortable and is in the best possible state. If treatment extends over a prolonged period, or if there is a substantial interval between the provision of information on the proposed treatment and the administration thereof, it is not sufficient if capacity is only present initially (when the information is given or treatment is commenced).

Material relativity means that the person concerned must have capacity in relation to the specific decision – i.e. a person may or may not have capacity depending on the complexity or significance of the situation. It is thus possible that a patient with mild dementia can still have capacity with regard to nursing measures, dietary preferences, etc., but lacks capacity in relation to medical decisions of greater complexity or of considerable significance.

To be distinguished from (mental) capacity are *legal capacity* and *capacity to act*. According to Art. 11 SCC, every person has legal capacity, i.e. can bear rights and obligations. However, only persons who are of age[29] and have (mental) capacity have capacity to act, i.e. are able to produce legal effects through their own actions (Art. 13 SCC). This means that children and adolescents under the age of 18 never have unrestricted capacity to act. If they have (mental) capacity, their actions can produce certain legal effects (limited *in*capacity to act). In particular, they can exercise strictly personal rights. For consent to medical treatment, (mental) capacity is sufficient. For this reason, minors with capacity must always consent to treatment themselves; they can no longer be represented by their parents. Less clear is the question whether minors with capacity can themselves contract with the hospital or physician, since the conclusion of contracts generally requires unrestricted capacity to act. However, prevalent doctrine assumes that, in this strictly personal domain, minors with capacity can enter into a contract independently (e.g. contraception).

28 BGE 118 Ia 236 E. 2b; BGE 117 II 23 E. 2a.
29 Under Art. 14 SCC, persons attain majority at the age of 18.

Patients who lack capacity in relation to the particular medical treatment under consideration cannot independently consent to, or legitimately refuse, the treatment.[30] They require representation, unless a valid, sufficiently specific advance directive is available which can be directly applied. A special case is that of urgent medical decisions where – in the interests of the patient – it is not possible to wait until a decision has been made by a representative; here (by way of exception), the physician is entitled to act in accordance with the patient's presumed wishes and objective interests.

The question of who is to represent a patient lacking capacity is regulated in Art. 378 SCC, which specifies *the persons who, in the following order, are entitled to act as representatives:* (1) persons appointed in an advance directive or power of attorney; (2) a deputy appointed by the Adult Protection Authority who is authorised to act as a representative in medical matters; (3) a spouse or registered partner who shares the same household as or regularly provides personal support for the person lacking capacity; (4) the person who shares the same household as and regularly provides personal support for the person lacking capacity; (5) the offspring, (6) the parents or (7) the siblings, if they regularly provide personal support for the person lacking capacity. If no representative is available in accordance with these provisions, if a number of representatives of equal standing (e.g. several offspring) cannot reach agreement, or if the patient's interests are otherwise at risk, then the Adult Protection Authority is to be informed.

The authorised representative is required to decide as the patient would independently if he or she had capacity (presumed wishes). Only in the absence of any evidence of *presumed wishes* is a decision to be made in accordance with objective interests, i.e. based on the medical indication. If the patient lacking capacity is conscious, he or she is to be involved, as far as possible, in the decision-making process (so-called *right of participation*).

Under Art. 377 SCC, the attending physician is required to draw up a *treatment plan* and to inform the representative about the proposed measures – in particular, the reasons, purpose, nature, methods, risks, adverse effects and costs, consequences of failure to treat, and any alternative treatment options – so that the representative can make an informed decision on the patient's behalf.

30 Cf. also Aebi-Müller 2014.

2. Assessment of capacity

The question how capacity can best be assessed is a matter of controversy. For example, opinions differ on the weight to be attached to cognitive elements.[31] Other questions raised are whether instrumental investigations, such as imaging procedures, can be taken into account in – or even replace – an assessment. The present guidelines do not assume that capacity is an objectively determinable finding. Rather, capacity is defined as a value judgement which is the product of reflection by the person performing the assessment, based on empirical evidence of the patient's thoughts and feelings. From this perspective, the findings of instrumental investigations can at best play a complementary role, by enabling a better understanding of mental processes.

2.1. Tools

Capacity assessment tools primarily relate to the US legal system and are mostly available in English.[32] These tools generally cover cognitive, evaluative and decisional ability, and in some cases also expressive ability.[33] While cognitive ability is usually tested as comprehension of information, the areas of evaluation and decision-making frequently lack a clear conceptualisation and guidance for application in practice. The implementation of evaluative ability is not clearly defined and is discussed in different ways; with regard to decisional ability, the emphasis is generally placed on logical, rational considerations. Expressive ability is tested, if at all, as the ability to express a choice.[34] Assessments generally take the form of structured or semi-structured interviews, where patients are confronted with their own treatment decision. A critical view should be taken of the use of vignettes, as they do not have the requisite relevance to the patient's specific decision-making situation.[35] The time required for an assessment varies between 10 and 90 minutes.

To be distinguished from specific assessment tools are (brief) tests – in particular, the Mini Mental State Examination (MMSE), which is merely used to screen for dementia and is not designed for capacity assessment. Studies have shown that the MMSE cannot accurately determine capacity.[36]

The instrument which has been most widely adopted internationally – and the only one published as a manual – is the MacArthur Competence Assessment Tool-Treatment (MacCAT-).[37] The MacCAT-T offers guidance on conducting an interview used to assess the patient's abilities and applying a rating system. It is re-

31 Cf. Hermann et al. 2016.
32 Cf. Lamont et al. 2013.
33 The terms generally used in the English-speaking world are *understanding, appreciation, reasoning* and *evidencing a choice*; these largely correspond to the terms normally used in Swiss legal doctrine – cognitive ability, evaluative ability, decisional ability and expressive ability.
34 Cf. Lamont et al. 2013.
35 Cf., for example, Silberfeld et al. 1993.
36 Cf. Fassassi et al. 2009.
37 Cf. Appelbaum & Grisso 1988.

garded as the most comprehensive tool, with the most convincing psychometric properties. However, as has been emphasised, it only represents an aid to the assessment process and does not replace clinical judgement.[38] Information on other tools can be found in Lamont et al. (2013). Particular mention should also be made of the Silberfeld questionnaire.[39]

Common to all the tools is the fact that primarily cognitive factors are assessed. This is also attributable to purely pragmatic considerations; the abilities going beyond comprehension of information and communication of a decision are difficult to operationalise and to evaluate reliably.[40] Although, by focusing on cognitive factors, many of these tools offer the advantage of a standardised, comprehensible assessment, they neglect emotional, intuitive factors and values. Critics have argued that the somewhat «mechanistic» approach does not adequately reflect either the complexity of assessment or relevant relational aspects in decision-making.[41] In addition, an approach focusing on formal requirements can give rise to pseudo-objectivity, with insufficient attention being paid to ethical/normative considerations.

2.2. U-Doc form for capacity assessment and documentation[42]

The U-Doc[43] was developed in response to criticisms of the cognitivist approach adopted by many standard tools. Rather than being a tool for measuring the abilities relevant to capacity, the U-Doc – in accordance with the principles set out in Section 2 of the guidelines – offers a set of criteria for justifying the ascription of *in*capacity.

The U-Doc is a form which can be used in a flexible manner – as an aide-memoire, as a decision aid, but also as a basis for discussion and/or documentation. The reason for the assessment and the results thereof are to be recorded. As well as cognitive factors, emotional factors and values are taken into account. While mild impairments in one of the areas assessed may be offset by abilities in other areas, this is not possible if severe impairments are present. Completion of the form is intended to promote self-critical reflection on the part of the assessor with regard to personal values and possible conflicts of interest.

38 Cf. Dunn et al. 2006.
39 Cf. Silberfeld et al. 1993.
40 Cf. Breden & Vollmann 2004.
41 Cf. Breden & Vollmann 2004.
42 The documentation form was developed and evaluated at the University of Zurich Institute of Biomedical Ethics and History of Medicine as part of the Swiss National Science Foundation (SNSF)-funded research project «Assessing decision-making incapacity at the end of life»; cf. www.nfp67.ch/en/projects/module-3-regulations-proposals-action/project-biller-andorno
43 Cf. www.ibme.uzh.ch/de/Biomedizinische-Ethik/udoc.html

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IV. INFORMATION ON THE PREPARATION OF THESE GUIDELINES

Mandate

In September 2015, the Central Ethics Committee (CEC) of the SAMS appointed a subcommittee to prepare medical-ethical guidelines on the assessment of capacity.

Sub-committee responsible

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PD Dr Julia Haberstroh, Frankfurt am Main
Professor Ralf J. Jox, Lausanne
Dr Roland Kunz, Zürich
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Consultation procedure

On 17 May 2018, the Senate of the SAMS approved a draft version of these guidelines to be submitted for consultation to professional associations, organisations and other interested parties. The comments received have been taken into account in the final version.

Approval

The final version of these guidelines was approved by the Senate of the SAMS on 29 November 2018.