



**Universität
Zürich** ^{UZH}

Lay Summary

Decision-making incapacity at the end of life and its assessment in Switzerland

Project team

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1. Background

Decision-making capacity/competence (DMC) can be considered as a gatekeeper for a patient's right to self-determination in medical/end-of-life decisions. Therefore, sufficient knowledge and careful evaluation of a patient's DMC are crucial.

The project departed from observations indicating that theoretical controversies, unclarities, and practical challenges in terms of DMC persist, and that little is known, in general and with particular regard to the Swiss context, about clinicians' knowledge, attitudes, and assessment practices.

2. Goals of the project

The goals of the project were threefold.

First, we aimed at providing an **overview and clarification of conceptual challenges related to DMC**. This included *theoretical reflections* on the general legal and ethical understanding of DMC, its constitutive elements in terms of mental abilities, the question of relativity regarding time, the specific decision, and the risks involved, and the ethical/normative dimension of DMC.

Second, we strived for a better understanding of the **current evaluation practice in Switzerland**. This comprised a *quantitative survey* among physicians in Switzerland in order to investigate practitioners' knowledge and attitudes regarding the concept of DMC, and their assessment practice, difficulties, as well as their need for more elaborated guidance and training.

Third, we wanted to develop and test **guidance and training materials**. This included the *conceptualization and design* of training and guidance materials, *training sessions and testings* of the guidance materials with practitioners including *qualitative interviews* to gain feedback, and *exchange and discussion* with experts in the field and various stakeholders, including the Swiss Academy of Medical Sciences (SAMS) in order to advance implementation on a policy level.

3. Methods

Our research goals required diverse research designs and methods including literature overviews and reviews, analytical and argumentative approaches, quantitative and qualitative empirical studies, and design methods.

4. Results

The research project has shown that the evaluation of a patient's DMC is a complex task, particularly



in so-called grey-zone cases (patients who are neither obviously competent nor obviously incompetent), conflicting moral values, and/or conflicting opinions among healthcare providers, the patient, and his or her surrogate or next of kin.

The findings of the quantitative survey and the feedback from the qualitative interviews indicate that physicians in Switzerland currently apply their own rules of thumb regarding DMC evaluations. These rules have been acquired over time and perhaps have proven clinically appropriate, but also evoke feelings of uncertainty and prompt the tendency to delegate or circumvent detailed DMC evaluations whenever possible. The high frequency of implicit assessments (rather than explicit evaluations) and referrals to specialists, and physicians' own beliefs that they are underqualified support these observations.

Regarding documentation of a patient's competence or incompetence, feedback from the interviews led to the impression that DMC is either very briefly documented by only indicating the final judgment, or not at all explicitly documented, at least in daily clinical practice. Detailed justification or a description of the underlying impairments are scarcely written up or must be inferred from the patient record. This observation contrasts with the interviewees' opinion that it is a moral requirement to give reasons for an incompetence judgment.

DMC encompasses a scope of discretion. Ethically normative considerations or value judgments are necessarily involved - implicitly or explicitly - and can be, but must not be, inappropriate, signaling unjustified paternalism. Thus, a subjective element is inevitable. Notwithstanding, a significant proportion of physicians is not aware of the proven impact of personal values on DMC evaluations preventing any critical reflection and correction of undue personal biases.

DMC concerns a patient's ability for self-determination, which is a complex concept that has been variously defined in different disciplines. In Swiss law, it refers to the *Fähigkeit, vernunftgemäß zu handeln*, which is further differentiated into *Willensbildungsfähigkeit* and *Willensumsetzungsfähigkeit*. For clinical practice, further specification of criteria is crucial.

A comprehensive review of the literature has shown that there are several good arguments for the inclusion of non-cognitive factors in DMC evaluations. The importance of emotions and values, beside cognitive criteria, has also been confirmed by the surveyed clinicians. However, compared to cognitive criteria, emotional factors are much more difficult to operationalize and thus to assess in a standardized manner. In addition, the assessment of non-cognitive factors requires a more context-specific and integral approach. These difficulties and special requirements have raised concerns that the involved scope of discretion could easily be abused, resulting in arbitrariness and undue paternalism.

Besides the definition of relevant mental abilities, the treatment of the patient or the assessment procedure deserves attention. It is crucial to be aware that a patient's mental abilities are not stable and can fluctuate over time, and can and should be enhanced and supported by means of appropriate communication and a range of different support strategies and measures. Ideally, the patient's DMC is assessed within a shared decision-making process and a supportive therapeutic relationship, as it has

been shown that more than half of the surveyed clinicians believe that their relation to their patients has a substantial influence on DMC evaluations. Within a trustful relationship, a co-constructive process of understanding and giving meaning to situations and experiences can evolve in ways that support and promote the patient's decision making, allowing the clinician to build a fuller sense of the patient and their concerns, which is particularly important for the evaluation of emotional aspects. An unstructured, narrative approach appears appropriate and better suited, as a structured assessment by means of a test or interview which runs the risk of a rather impersonal or mechanistic assessment of the patient that does not take appropriate account of patients' needs or decision-making preferences and styles.

As with regard to the developed trainings and guidance materials (named UUKit), clinicians reported several benefits. Among others, the tool educated and sensitized for the topic, effectively supported clinicians in clarifying a patient's DMC, increased confidence in one's own judgment, provided relevant terms for formulating and communicating a judgment, and helped reflecting personal biases. Most problematic was the required effort and time for application of the tool and smooth implementation of the assessment procedure in routine clinical care.

5. Significance of the results for science and practice

The results of the research project have shown that DMC evaluations are challenging in grey-zone cases, and that healthcare professionals in Switzerland feel underqualified to deal with the task while appreciating the ethical and legal relevance of the topic. Consequently, relevant situations are not always identified, or explicit evaluations are circumvented or ceded to others. For the future, it is therefore important to raise awareness of the topic among healthcare practitioners and to better educate and train them. The UUKit has proven to be of value for this purpose.

Furthermore, besides educational interventions, we regard it as crucial to give DMC a stronger emphasis in clinical practice. The research project has shown that implementation of the UUKit into the clinical processes can be difficult. Explicit DMC evaluations are not yet routine, and it takes time and effort, from the institution's (e.g. a hospital's) side as well, to change current clinical practice and foster acceptance of a new procedure/tool. First, general awareness of the topic within the institution should be increased in order to ensure identification of relevant cases. Second, there should be time and means provided to evaluate and discuss cases. According to the interviewees, interprofessionalism, or more generally exchanges with colleagues, are essential in the evaluation of DMC. Discussion with others not only reduces uncertainties and fosters reflection on personal biases, but may also support the transition from training to clinical practice through mentoring opportunities. Third, interventions should be established that enable the explicit and convenient documentation of DMC within the existing documentation system. The development of the electronic health records will provide additional opportunities in this regard. The documentation form that was developed as part of the project may serve as a useful template that can add value to existing documentation systems.

Thanks to close collaboration with the Swiss Academy of Medical Sciences (SAMS), some of the project's insights and outputs have been discussed within the subcommission of the Central Ethics Committee (ZEK) on DMC and will be integrated in the resulting SAMS guidelines.

