

## SUMMARY

Patient competence is the subject of the present dissertation, which reflects its author's quest for criteria of the said concept. The leading research question in this quest is: how ought patient competence to be assessed? This main question is divided into sub-questions relating to the rationale of patient competence, the relevance of patient competence, legal consequences in competence assessment, criteria for assessing patient competence, problems in competence assessment, the underlying norm in competence assessment, preconditions of competence assessment, the conformity of available criteria with these preconditions, test-like instruments for assessing competence, the psychological validity of criteria in the light of everyday decision-making, the role of emotionality in patient competence, possible support during competence assessment, and indications for such assessment.

With the exception of the overview, which forms the *first* chapter (see below), this dissertation's chapters are papers that have been published elsewhere, and three of them have one or more co-authors (see the Preface for bibliographic data).

The *second* chapter of this dissertation gives a legal-ethical outline of the research context, treating competence in relation to clinical trials using patients with severe mental illness as subjects. It enumerates several (international) legal and ethical documents pertaining to human experimentation. These documents have in common that they establish valid consent on behalf of the participant as a necessary condition for legitimate subjection of the participant to research interventions. One of the necessary conditions for the validity of consent is the consenting person's competence. Also, the chapter gives a brief comparison with four other European countries and a discussion of normative aspects of competence to consent to participation in research, which aspects relate to the tension between the goal of protecting vulnerable patients and the goal of favouring scientific progress. It ends with a sketch of the decision-making procedure called "experienced consent".

Chapter *Three* reports on a qualitative empirical research study into assessment of patient competence in a (psycho-)geriatric care setting. During this study, health care professionals were observed in the daily course of their activities and later interviewed about the observed results. The original aim of the study was to make an inventory of criteria used by health care professionals in their assessment of patient competence.

Unexpectedly, the study revealed that patient competence is not a topic of discussion at all in the observed practice, although the setting had expressly been selected so as to increase the chances of encountering patients with questionable ability to decide for themselves. Apparently, there is a discrepancy between the pivotal place competence occupies in theoretical models of decision-making, and the actual attention this concept receives in daily health care practice. This result has been confirmed in numerous informal contacts with other health care professionals and academic researchers.

In the chapter, the significance of these factual research data for the law is explored. It is argued that these data must not be taken as signalling a shortcoming in health care practice, but that they can methodically serve as an occasion to critically re-examine the legal model, notably the concept of competence (see Chapter 4), available empirical approaches for assessing competence (see Chapter 5), psychological considerations on competence assessment (see Chapter 6), and the legal role of the health care professional with respect to patient competence (see Chapter 7).

In the *fourth* chapter, the critical examination of the concept of competence is taken up. After a brief introduction to different approaches used in relation to patient decision-making competence and to the literal meaning of the term "competence", an outline of four necessary conditions for competence assessment is given, starting from a task-specific definition of the concept. These conditions are (1) that the kind of task be known, (2) that it be known what constitutes sufficient fulfilment of the task at hand, (3) that the required abilities and qualities be known, and (4) that it be ascertainable whether or not the person in question actually has the required abilities and qualities.

Application of these conditions to the field of health care makes us substitute health care decision-making for the task at hand in the first condition. Since health care decision-making may involve vital interests, such as a person's life, somatic and mental health, functional ability and well-being, of a vulnerable group, i.e. patients, this task entails an important responsibility.

From the second condition, it is immediately clear that competence assessment includes a normative dimension: a threshold is needed to distinguish sufficient from insufficient fulfilment. It is suggested that decision-making fostering beneficial health care tailored to the personal needs and values of the individual patient ought to comprise the necessary threshold. The chapter underlines the necessity of patient involvement in decision-making on the assumption that health related

interests are too individual to be expressed in commonly applicable terms and too personal to be wholly knowable for health care professionals. As to the third condition, such decision-making requires adequate judgment of the patient's own health related interests. The qualities and abilities presupposed for that sort of judgment fall into the following four elements, implying four cumulative criteria of patient decision-making competence, namely cognitive content (knowledge of facts and personal values), manipulation of cognitive content (analysing, reasoning, prioritising, integrating etc.), freedom of will, and means of expression. The reader should note that possession of these qualities enables the patient to decide in favour of beneficial health care, but does not compel him to do so.

The fourth condition relates to the testability of patient incompetence. Testability of the abilities and qualities required for patient competence, provides the assessor of competence with an empirical basis for deviating from the assumption of competence, as the occasion arises.

The *fifth* chapter embroiders on this notion of testability by reviewing some empirical approaches for assessing patient competence or incompetence. It distinguishes between a negative approach, which focuses on identifying psychopathologic conditions that impair sound decision-making, and a positive approach, which attempts to assess whether a patient actually has the required abilities and qualities. The chapter shows that none of the reviewed approaches offers a reliable and valid method for competence assessment. Typical of the negative approach is that it practically includes the whole range of psychiatry. This is unsatisfactory, because it unsettles the principle of autonomy with respect to psychiatric patients. In other words, the negative approach may be very sensitive; but it lacks specificity. The insufficiency of the positive approach can be attributed to the fact that the abilities and qualities measured by the tests in question have limited relevance in the context of patient competence.

Among other things, the chapter's commentary addresses situational influences in patient competence and competence assessment, of which a weighty one is the health care professional herself. After all, she shapes the decision-making task for the patient and judges whether he is able to perform it. Patient behaviour associated with incompetence might be reducible to mental incapacity indeed, but it may just as well be the consequence of a lack of situational support. Such support is possible with a view to all four qualities and abilities mentioned in the previous chapter. In this regard, the assessor of patient competence has the duty of structuring the situation so as to optimise the chances that the person under investigation meets the criteria of competence. In other words, the

assessor should not simply attempt to establish the patient's incompetence, but rather try to get the person to competently decide himself.

*Sixthly*, after the empirical review of Chapter 5, the next chapter embarks upon a psychological analysis of the concept of patient competence. It concentrates on two elements that are part of common models for patient competence, namely conscious motivation of decision-making in the first place and consistency of information-processing in the second. By means of some illustrative psychological theory and several research examples, it is argued that in general, the aforesaid models aim too high: application of these two elements as standards for competence would easily exceed the way in which persons usually make decisions, certainly when we are talking about patients who are not quite their normal selves after they have been overcome with sudden disease.

An investigation of the potential significance of emotionality as criterion of competence, leads to the conclusion that a patient's emotions do have relevance to competence assessment in that they may be indicative of this patient's interests and values, but also to the conclusion that the emotions' relevance in the context of patient competence is limited in that they do not decide the matter just like that. Furthermore, the inherent impossibility of psychometric tests for measuring patient competence is demonstrated -at least for those cases which raise the need for tests- by employing psychometric theory and relating that theory to the rationale of the concept of competence and the underlying principle of respect for patient autonomy. At the end, this chapter points to the necessity of obtaining an explicit normative framework for passing judgments on patient competence.

In the previous chapters it was noticed that clear, concrete, fair criteria of patient competence which can be reliably and validly assessed at that, are lacking. In view of this lack, it is not surprising that health care professionals only rarely venture upon such an assessment in their daily practice. The *seventh* chapter, lastly, inquires into the question whether any grounds can be found in the law for the health care professional to get round judging patient competence. It does so by critically re-examining the role of the health care professional in the legal model.

The result of this is that the health care professional is indeed shown to have reasons justifiably to steer clear of explicit competence assessment: generally speaking, the professional may want to appeal to the assumption of patient competence, when she thinks that there is no legitimate trigger for calling it into question. The deeper cause of this is the fact that the health care professional is expected to evaluate to a

certain extent herself the personal interests of her patient, and to incorporate this evaluation in her "medical" decision-making concerning the patient. If under these circumstances the health care professional succeeds in persuading the patient and any other persons involved (e.g. family members or other potential representatives) to assent to the interventions proposed by her, she is permitted to act on the assumption that the decision is representative for the interests of the patient. Insofar as the health care professional rightly takes care of judging her patient's interests -and properly so-, there is no -or, at any rate, less of a- need for the patient to do this; and insofar as the patient has no task in judging his interests, it directly follows from the task-specific character of the concept that competence does not matter in this regard, and hence does not have to be assessed. And that demonstrates that from a legal point of view, the health care professional can often refrain from assessing competence, or even that she has to refrain from such assessment. Finally, attention is drawn to the question how professionals could be able to judge their patients' interests, and to the possible use of the so-called values history in this respect.

The *Overview* chapter (Chapter 1), preceding the publications summarised above, explicates the interrelationship between these publications. In this overview, it is argued that in organising and implementing patient care, health care professionals should try to create circumstances under which it is justified to appeal to the assumption of competence conceived as a presumption of law. The obligation in question amounts to doing everything possible to take seriously the subject of the patient and his wishes, experiences, questions and hesitations, and to doing their utmost to shape professional care interventions in such a way that they are adapted to the patient's values, interests, needs and lifestyle.

The incidence of cases in which an assessment of patient competence is nevertheless necessary, with transfer of the decisional power to someone other than the patient as a possible consequence, cannot be totally ruled out. The exposition in hand proposes that they be limited to those situations where one or both of two strictly defined legitimate triggers present themselves. On the premise that a test of competence is about testing the quality of the decision-making process, the author defends as criterion for those -ideally- exceptional cases a recognisable reasons approach, which requires the patient to demonstrate to the assessor of competence, usually the health care professional in charge of treatment, that -and why- his choice is accountable in light of his personal values and perspective on life and death.

As to its practical implications, the combination of the discussed legitimate triggers and the recognisable reasons approach, as visualised in Figures E, C and K, resembles the sliding scale for competence assessment. However, in comparison with the sliding scale, the model defended by the author has the triple advantage -firstly- of being more consistent, in that it does not pretend to be a test of competence when such a test is actually not the matter, -secondly- of being more protective, in that it includes an additional professional safeguard in cases where the sliding scale would make no demands on patient competence worthy of mention, and -thirdly- of being more instructive, in that it supplies the assessor with further guidance if a test of competence must indeed take place.