Inhoud

Preface

Few legal constructs carry the real-world impact of decision-making competence. In liberal democratic societies, people who are deemed competent are generally entitled to make most personal decisions for themselves. By way of contrast, people who are found to lack decision-making competence may be deprived of the rights to decide about the most fundamental aspects of their lives. They may, for example, lose the power to sign a contract, convey a gift, write a will, choose where to live, marry, vote, and dispose of criminal charges. When it comes to health care, patients found to be incompetent will yield the right to decide about their medical treatment, and even their participation in research, to a third party charged with representing their interests and desires.

Given the critical nature of decision-making competence – which has been called the 'queen' of concepts in mental health law – its relative neglect for many years is surprising. Until the late 1970s, there was almost no literature, either theoretical or empirical, on decisional competence in the context of healthcare and medical research. Only then, stimulated by growing interest in the doctrine of informed consent to medical treatment, were the first efforts made to conceptualize an operational definition of decision-making competence. This seminal work by Loren Roth and his colleagues at the University of Pittsburgh in the U.S. set the stage for explosion of interest in the concepts associated with decisional competence that was soon to follow.

Our collaboration on decision-making competence, which began in the late 1980s, was built on a modified version of Roth et al.'s operationalization of decisional competence, using the four criteria that are familiar to most health professionals today: the abilities to understand relevant information, to appreciate its implications, to reason with it, and to evidence a choice. We developed a set of research instruments that embodied this quadripartite standard for the MacArthur Treatment Competence Study (funded by the John D. and Catherine T. MacArthur Foundation), the most extensive empirical study of the subject to that point in time. However, as that study was concluding, it was apparent to us that the time-consuming instruments we had developed would be extremely difficult to use in clinical settings. What was needed was a tool that allowed a brief but thorough assessment of the four functions underlying decisional competence, could be customized to the particular treatment decision at hand, and could be used clinically and for research purposes as well.

From this insight, the MacArthur Competence Assessment Tool for Treatment (MacCAT-T) was born. Recognizing a similar need for clinical research settings, a few years later we developed a companion MacCAT for clinical research (MacCAT-CR). What has happened in the years since has been enormously gratifying to us. The availability of the MacCATs triggered an efflorescence of research on decision-making competence. Scores of studies have been performed with each of the MacCATs, producing extensive data that have helped to identify those conditions and circumstances most likely to lead to impaired competence. At the same time, creative approaches have been developed to

support the decision making of persons with some degree of decisional impairment so that many of them can make competent decisions for themselves, rather than surrendering that power to substitute decision makers.

Moreover, the conceptual model and structure of the MacCAT has had resonance for decisions beyond those found in medical treatment and research settings. The MacCAT model has been adapted for assessing competence to participate in criminal proceedings, complete an advance directive and select a proxy decision maker, manage finances and activities of daily living, and make decisions about where to live. Modified versions have been developed for use with minors, and the MacCATs have been translated into Spanish, Mandarin, Hebrew, Dutch, and French, among other languages. The MacCAT's conceptual model has proven useful for teaching trainees in medicine, psychology, law and other disciplines about decision-making competence. And the MacCAT instruments themselves are routinely used to screen participants in clinical research and to assess the capacities of patients whose decision-making competence is in question.

This book introduces the Dutch versions of the MacCAT-T and MacCAT-CR, based on the work of Irma Hein and her colleagues, embedding them in the legal and ethical context of the Netherlands and Belgium. The chapters also illustrate the role of assessments of decisional competence in a variety of contexts, ranging from psychiatric treatment to end-of-life decisions, to care for the elderly. Given its scope, it should be of immense assistance to Dutch-speaking clinicians and researchers, who will now be able to draw on a body of comparative research using the MacCATs from around the world. We are delighted to see the reach of the MacCATs and the model on which they are based extend to our colleagues in the Netherlands and Belgium, in the hope that the instruments will help to improve the assessment process for decision-making competence to the benefit of clinicians, patients, and family members alike.

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