

Mental Capacity: In Search of Alternative Perspectives

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INTRODUCTION

Respecting patient autonomy is an important value in (mental) health care. In many jurisdictions, this value is translated into the concept of informed consent, which implies that before treatment or research can take place, the patient or research subject should give consent on the basis of relevant information which is provided by the health care worker or researcher. The concept of informed consent is based on the *volenti non fit injuria* principle, which states that a person is not harmed by acts of others to which he or she has consented (Feinberg, 1986).

One of the preconditions for informed consent to be valid is that the patient or research participant has mental capacity (Faden and Beauchamp, 1986). In order to execute his or her rights, the person involved ought to have the capacity or competence to decide (decision making capacity) about treatment or research participation. In case the person lacks such decision making capacity, others may have authority to decide for the patient (proxy consent).

In a number of clear-cut cases, judgments about capacity are uncontroversial, as in the case of a comatose patient or a newborn or very young infant. The issue of mental capacity generally arises (and becomes more controversial) with regard to patients who belong to 'vulnerable' groups: the cognitively impaired elderly, the mentally handicapped, individuals suffering from mental illness and children (Berghmans, 2001).

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Given the moral and legal importance of an assessment of decision making capacity, it is not surprising that in the last decades in medicine, law and ethics the debate with regard to this notion and its assessment has received increasing attention (Glass, 1997; Berghmans, 2000, 2001). Questions addressed in the debate and the growing literature concern philosophical, ethical, legal, medical, psychological and empirical issues.

Philosophical and ethical questions concern primarily the concept of mental capacity or decision making capacity, and the values involved. What exactly are we talking about? Is capacity a part of the description of a person in the way that his height and weight are part of his description? (Pincoffs, 1991) And if not, how should we conceive this concept then? What moral values have relevance for the concept of capacity and how should these be taken into consideration?

Legal questions concern the protection of persons who lack decision making capacity in treatment and research decisions and the authority of proxy decision makers as well as procedural issues aiming at responsible and just decision making.

Medical and psychological aspects of capacity involve capabilities which are recognised as necessary and/or sufficient for a person to be considered to have decision making capacity, and the way in which these capabilities can be assessed.

Empirical issues concern the development of instruments to assess capacity as well as research in which the capacity of particular patient groups is assessed and/or compared with non-patients or other groups of patients.

Mental capacity has been much debated since the publication of the seminal article by Roth et al. (1977). And in the practice of mental health care, a need is felt for tools which might help practitioners to assess the capacity of patients (Berghmans, 2001).

As the different contributions to this thematic issue show, there is a certain discontent with the mainstream approach to mental capacity and the accompanying development of instruments to assess mental capacity. This mainstream approach focuses on standards and criteria which may be applied in the assessment of capacity, and which are the basis for the development and validation of tests and instruments. This approach can be characterised as cognitivistic and rationalistic; it is based on specific presumptions with regard to decision making, in which autonomy and rationality are central. The need is felt to develop alternative approaches to mental capacity which address issues which are not or underdeveloped in the mainstream approach: emotion, identity, practical knowledge and reasoning, narrative and communication. Alternative approaches which are rooted in hermeneutic, narrative and feminist philosophy may contribute to a richer and more adequate account of what it means to have capacity and how to deal responsibly with this issue in the everyday practice of mental health care.

The development of alternative models for the assessment of capacity is linked to the rise of alternative models more generally in bioethical theory, so that autonomy and rationality are generally less dominant than they used to be (Dickenson and Parker, 1999; Widdershoven, 2000).

ISSUES OF CONSENSUS

Although there are a number of issues of debate, there are also a number of issues with regard to decision making capacity over which consensus has arisen (Welie et al. in press).

Firstly, it is agreed that there ought to be a *legal presumption in favour of capacity*. Unless there are reasons for the opposite, patients ought to be considered to have capacity. This presumption applies equally to all groups of patients, i.e. those suffering from somatic illnesses, as well as those who suffer from mental illnesses, neuropsychiatric disorders or are mentally handicapped. This presumption may be viewed as expressing a priori respect for the autonomy and dignity rights of persons (Carpenter, 1999). This means that the burden of proof lies with the health care worker who takes the view that a patient lacks decision making capacity (Weisstub, 1990). This legal presumption, however, may become problematic in cases when medical or other interventions are not primarily in the best interest of the patient, as in research participation (Berghmans and Widdershoven, 2003). The presumption of capacity may then permit patients with impaired decision making capacity to sign consent forms they do not understand and to participate in risky and/or burdensome biomedical research protocols without being appreciative of what interests are at stake. This can be particularly problematic in case of biomedical research which involves risks and burdens to the subject, and no or little promise of benefit.

Secondly, it is agreed that capacity is *task specific and decision relative* (President's Commission, 1982; Buchanan and Brock, 1989). As already stated, decision making capacity is not directly connected to specific disorders or diagnoses. Neither implies a judgment about decision making capacity a general qualification of the person involved. Capacity is always related to a specific treatment or research decision. This means that patient A. may lack capacity to decide about decision X, but at the same time may have capacity to decide about decision Y (Buchanan and Brock, 1989).

The decision-relative approach to mental capacity implies that more is asked of a patient when a complex decision is involved, than in case of a less complex, more straightforward decision. In terms of understanding complex decisions are more demanding.

There is controversy whether mental capacity above that ought to be considered in a risk-relative sense (Buchanan and Brock, 1989; Culver and Gert, 1990). Risk-relativity would imply that a more demanding standard is applied in case the decision of the patient involves greater risks (Checkland, 2001; Buller, 2001). This approach is based on the conviction that our concern for the patient's welfare requires that a higher lever of capacity should be demanded for decisions pertaining to life and death, than for decisions which may result in lesser harms (Berghmans, 2000, 2001). Against this approach two major objections are raised (Elliott, 1991; Wicclair, 1991; Wilks, 1999).

The strongest objection is that it supports an asymmetric view of capacity: an individual may at the same time have capacity to consent to treatment but lack capacity to refuse it. Many consider this implication counterintuitive, because it rejects the apparently intuitive ‘principle of symmetrical competence’ (Checkland, 2001). Proponents of a fixed standard who reject a risk-related approach pose the question: ‘what level of capacity is necessary for an individual to make a certain decision?’ Proponents of a risk-related standard pose another question: ‘what level of capacity is necessary for an individual to grant that individual decisional authority with regard to a specific choice?’ The first approach focuses on decisional capability, the second on decisional authority. The latter perspective does not exclusively focus on individual capabilities, but incorporates risk as a relevant factor in deciding what level of decision-making capabilities is required (Brock, 1991).

The second objection is that the risk-related approach conflates two issues: on the one hand, the question whether or not an individual has capacity, and on the other hand, whether or not his or her choices should be respected or might be overruled on paternalistic grounds (Culver and Gert, 1990; Buller, 2001). Those who argue against the risk-related approach defend that a two-step model ought to be followed: first, the assessment of capacity, and second the question of whether to overrule the decision of the individual. Upon this view, decisional capacity and decisional authority are separate questions. And as already said, proponents of a risk-related approach see capacity and authority in a connected sense.

Thirdly, consensus exists with regard to the *quality of the decision making process* which ought to be decisive for a judgment about capacity. It is generally recognised that the *outcome* of the decision making of the patient cannot be the basis for a judgment about capacity. Even if this outcome is considered unwise, irresponsible or irrational by healthcare workers or others, it depends on the decision making process as well as the values involved whether the decision should be considered to be a sign of capacity.

Fourthly, agreement exists that decision making capacity involves a *normative judgment* (Appelbaum and Roth, 1982; Buchanan and Brock, 1989; Berghmans, 2001). Given the fact that a judgment about capacity has implications for the rights of the patient, and given the fact that such a judgment involves an answer to the question whether or not the decision making of the patient is ‘good enough’ to deserve respect of the health care worker, values inherently are involved in such a judgment. Obviously, this is not to deny that descriptive aspects also are involved.

IN SEARCH OF CRITERIA

A major focus in the literature so far is on standards and criteria which may help to assess mental capacity (Berg et al., 1996; Glass, 1997; Welie, 2001).

Broadly speaking, the following four standards or criteria can be distinguished: (i) the capacity to make and express a choice; (ii) the capacity to understand relevant information; (iii) the capacity to evaluate the character of the situation and possible consequences; and (iv) the capacity to handle information rationally (Berghmans, 2001; Berghmans and Widdershoven, 2003).

The capacity to make and express a choice is most basic and presupposed in the three other criteria. This criterion relates to the capability of a person to express (verbally or non-verbally) what she has decided. Obvious cases of lack of capacity are patients in a persistent vegetative state, newborns and the severely mentally handicapped. Hard cases are those in which it is unclear whether a person expresses a choice or decision, or whether something else motivates a person in a particular way. An example is the case of a dementia patient who 'refuses' to be tube-fed. Is it the patient's wish not to be tube-fed, or is it merely so that she is uncomfortable (e.g. irritation of the nose)?

The capacity to understand relevant information emphasises the importance of a patient's comprehension of information related to the issue at hand. Obviously, this presupposes disclosure of relevant information. In regard to this standard it is necessary to distinguish between the mere capacity to understand information, and actual understanding. Merely having the capacity to understand is not a sufficient condition for actual understanding. A person may have the intellectual capabilities to understand information, but nevertheless may misunderstand information as a result of selective attention, wishful thinking or defects in the handling of information. An illustration of such mechanisms is the therapeutic misconception, which may undermine the moral and legal validity of informed consent in research. The therapeutic misconception occurs when a subject fails to appreciate the distinction between the imperatives of clinical research and of ordinary treatment, and therefore inaccurately attributes therapeutic intent to research procedures. This may lead to an underestimation or even failure of perception of risks and disadvantages in relation to research procedures (Lidz et al., 2004).

The capacity to evaluate the character of the situation and possible consequences differs from the mere ability to understand information in the abstract by requiring that a patient is able to apply the information in her own personal situation. It requires the patient's recognition that the disclosed information about the disorder, prognosis and treatment is significant for and applicable to her own circumstances (Grisso et al., 1995). In this context the issue of the relationship between capacity and illness awareness and insight can be raised. Some take the view that denial of illness implies incapacity (Gutheil and Appelbaum, 1982). This view implies that a person who does not identify with the psychiatrist's diagnostic view may be disqualified on the ground of lack of insight (Roe, Lereya and Fennig, 2001). But although the patient may appreciate and evaluate her own condition and situation differently from the psychiatrist, this does not necessarily imply

that she does not evaluate and appreciate her situation. How a patient evaluates the information at least partly depends on the context in which this evaluation takes place. And although different medical options (and their respective consequences) may be described objectively, the valuation of these options and consequences is related to the goals, values and norms a particular patient considers to be important in her life. Further, evaluation and appreciation also have an affective dimension (Charland, 1998). In the literature and debate on capacity, affective dimensions are generally considered to have a negative impact on capacity because they reduce cognitive performance (Bursztajn et al., 1991). But emotions also may play a positive role. Emotions can be considered as sources of knowledge because they provide vital information about the feelings somebody has. They also may tell us what goals, values, and states of affairs a person considers important (Nussbaum, 1990).

The capacity to handle information rationally refers to a patient's ability to employ logical processes to compare the benefits, burdens and risks of treatment options or research interventions. This involves the capacity of practical reasoning (Benn, 1988). With regard to this standard, confusion may arise about the proper meaning of the concept of rationality. A decision sometimes is considered irrational merely because the patient's choice is unconventional. Here, the irrationality to which this standard properly refers pertains to poor logic in the processing of information, not to the choice that is eventually made. Thus, a patient who can understand, appreciate and communicate a decision may still be impaired because she is unable to process information logically, in accordance with her preferences (Berg and Appelbaum, 1999).

The four discussed standards presuppose different (psychological) capabilities that may be relevant in the assessment of decisional capacity. Taken separately, the first criterion exclusively focuses on whether a choice is made and expressed and does not address aspects of the decision making process. The three other criteria address specific elements of this process.

What standard or criterion (or combination of standards) is applied in assessing capacity influences the chance a patient will be considered to have or to lack decision making capacity (Berghmans and Widdershoven, 2003). One study investigated the proportion of psychiatric and medical patients who were considered impaired in their decision making capacities in relation to each of several major legal standards for determining capacity to consent to treatment. Different groups of patients were identified as 'impaired' depending on the standard used: one measuring understanding, another measuring reasoning, and a third measuring appreciation. The outcome of this study suggests that, other than has been suggested in the literature, the single standards commonly used do not form a hierarchy. The authors conclude that although the standard of evidencing a choice is clearly less demanding than the three other standards, there is no clear hierarchy of rigor among the remaining three (Grisso and Appelbaum, 1995).

DEVELOPMENT OF INSTRUMENTS

Presently, much attention and energy is given to the development of instruments to (help) assess mental capacity (Kapp and Mosman, 1996; Welie, 2001; Vellinga et al., in press). A number of instruments apply hypothetical cases or vignettes, whereas other methods involve the (semi-)structured interviewing of patients. (A sophisticated example, the MacCAT-T is critically evaluated in the paper of Breden and Vollmann, see below).

A central question relating to the use of ‘objective’ instruments to assess capacity is whether or not such instruments really ‘measure’ capacity, or something other than capacity (Berghmans, 2001). Sometimes, tests only measure memory function (by asking the subject to describe in her own words what information she has received). And in case instruments use hypothetical case examples or vignettes also the focus lies more with the patient’s capability to reproduce information than on actual capacity to decide.

Instruments cannot replace the judgement of a physician and because the assessment of decision making capacity involves a normative judgment, a statistical approach is not justified (Vellinga et al., in press). Instruments by themselves cannot decide what threshold is applicable in order to decide whether or not the patient has capacity. Nevertheless, instruments may contribute to responsible decision-making by providing information about relevant capabilities of the patient.

EMPHASIS ON COGNITION AND RATIONALITY

The currently dominant approach towards issues of decision making capacity can be characterised as cognitive and rational. A number of common presuppositions of this approach can be distinguished (Berghmans and Widdershoven, 2003):

1. an emphasis on concrete, mostly cognitive, abilities of a person (decision-making; understanding of information; rational handling of information);
2. an emphasis on distinguishing between patients who have and patients who do not have capacity, and not on promoting capacity;
3. a lack of attention to what actually moves a person or what a particular choice or preference means for that person;
4. a lack of attention to the context.

IN SEARCH OF ALTERNATIVE VIEWS

In light of the dominant cognition focussed and rationality centered approach, which is connected to a particular view on decision making in general and decision making capacity in particular, the question arises whether particular groups of

mentally ill patients may become too vulnerable for judgments of incapacity. Because mental illnesses such as depression and schizophrenia and neuropsychiatric disorders such as Alzheimer's disease involve defects of cognitive and other mental processes, a focus on cognition and rationality may easily lead to a judgment that such patients lack decision making capacity. The application of standards, criteria and instruments based on rational judgment and faculties of cognition may lead to discrimination of the mentally ill.

This raises the question whether alternative approaches towards mental capacity would do more justice to such vulnerable groups of patients. Generally, in the dominant approach little or no attention is given to issues of emotion and narrative, identity and identification, and dialogue and deliberation (Berghmans, 2001; Berghmans and Widdershoven, 2003). Such concepts are addressed in philosophical approaches like hermeneutics, narrative ethics and feminist ethics/ethics of care. Up until now the contribution from such philosophical approaches to the debate on decision making capacity has been negligible. This special issue wants to present these approaches as alternative or complementary to the rationalistic approach.

Benaroyo and Widdershoven develop a hermeneutic perspective on mental capacity. In their view, the contribution of hermeneutic philosophy to the ethics of clinical care has been mainly by way of its critical approach to traditional models of medical decision making: it criticizes the ideal context-free knowledge of the dominant bioethical paradigm and insists on the context-bound character of the meaning of an ethical action and decision. Hermeneutics sees applied ethics as an interpretative attempt to understand which action is morally meaningful in a specific clinical situation with regard to the patient's and institutional narratives, and to the confrontation thereof with a meaningful account of a singular caring project.

Central in Benaroyo and Widdershoven's argument is the importance of practical reasoning. Competence is seen 'as a form of practical reasoning/practical understanding' (connected to the Aristotelian concept of *phronèsis*). They understand patient competence as correlative to the capacity of the caregivers.

To understand the patient's situation requires effort and care, imagination and perceptiveness, which involves an interpretative process in the realm of a dialogue. Patient competence is not primarily a matter of being able to reason (central in the dominant approach to mental capacity), but of being able to interpret the world and to respond to it.

The focus of Benaroyo and Widdershoven's paper is not so much on how to *assess* mental capacity, but on how to *develop* capacity and help patients to become more competent: to be able to live out their lives in such a way that they develop their identity in relations with others.

The central question in each and every case is what the patient's behavior means in the specific situation and what reactions of the caregiver are adequate. The Gadamerian question is whether a solution can be found in which the perspective

of the patient and that of the caregiver can be merged, so that both parties are satisfied.

The focus of *Higgs*' paper on the contribution of narrative ethics to issues of capacity is on narrative understanding as a route to assessing aspects of life that present moral concerns, in particular about dilemmas of capacity. "If we must judge people, we must first struggle to understand them." *Higgs* presents narrative understanding not as an alternative to the cognitive/rational approach, but as necessarily complementary.

Starting his article with an outline of narrative ethics, and considering the contribution of narrative ethics to the issue of mental capacity as 'work in progress', *Higgs* argues that in order to achieve respect for individual autonomy in the doctor-patient relationship, an understanding of what the patient wants to happen is required. Professionals should ask and listen, and the patient should know what her own choices are. However, part of the problem posed by medical encounters is that illness or disease may make all three of these things problematic, and once a patient's competence is questioned, the possibility of her being able to tell her story, or of such a story being pieced together, becomes remote. *Higgs* here sees the risk of a return to 'old fashioned paternalism' where the professional is given privilege and priority over the patient.

Ultimately, *Higgs*' contribution deals less with the issue of *assessing* mental capacity and competence, as with important aspects of the *context* of such an assessment. This is reflected in the 'techniques' which may be used to create a fuller narrative that he suggests: using imagination or empathy; seeing the account from the different perspectives of those actually involved in the problem; challenging the routines of professional behaviour; and making explicit and bringing together the different arguments and attitudes of those considering the case.

In *Maeckelberghe*'s paper, the contribution of feminism and care ethics to questions of mental capacity is explored. Presenting an ethic of care, seen as a particular form of feminist ethics, *Maeckelberghe* puts 'the relational self' and 'relational autonomy' center stage. The notion of the relational self is critical of libertarian individualistic and rationalistic conceptualisations of autonomy which are based on the image of the solitary, unencumbered individual who pursues a life course which is independent of others.

The feminist approach elaborated in this paper proposes a shift away from this perspective: the main question is not how competent or autonomous this person is, but how we can enable this woman or man in attaining autonomy and consequently how we can advance her or his competency in exercising autonomy. From a practical point of view, this brings in a focus on what means should be used in order to enhance someone's competence. As in the hermeneutic perspective, the context gains importance. Capacity can be reduced or enhanced by the context in which it is exercised.

As in *Benaroyo* and *Widdershoven*'s paper, in this paper attention shifts away from the care receiver to the care giver. "A caregiver will need to develop moral

skills to avoid the pitfall of undesirable paternalism that can permeate assessment of capacity.” Maeckelbergh concludes that assessment of capacity comprises a multifold and complex grid: a mapping of the situation in which a case is situated and in which the patient is related to a number of people.

The contribution of *Breden and Vollmann* introduces the MacArthur Competence Assessment Tool—Treatment (MacCAT-T) and critically examines its theoretical presuppositions. This instrument, developed to contribute to an assessment of decision making competence ‘in a more objective and reliable way’, is presently considered to be a gold standard in clinical psychiatry. It is a semi-structured interview to assess and rate several abilities of a patient: understanding the disorder and treatment, appreciation, reasoning, and expressing a choice. Breden and Vollmann recognize that up to now the MacCAT-T is ‘one of the most sophisticated assessment tools at hand’, because of the clear conceptualisation and precise definition of criteria. It also has high quality standards in objectivity, validity and reliability, and it is based on broad basic research. Above all, its excellent applicability in clinical practice has been certified in several empirical studies. Nevertheless, upon closer examination the central premises of a cognitive bias are open to serious challenge.

On the basis of thorough empirical, methodological and ethical critique Breden and Vollmann argue that the cognitive bias that underlies the MacCAT-T needs to be modified. Empirically, there is reason to believe that cognitive abilities are a necessary, but not a sufficient condition for mental capacity. A methodological challenge—along a number of different lines - of the MacArthur model also involves a rejection of its basic assumption that competence is a cognitive notion. An ethical argument Breden and Vollmann raise against the MacCAT-T is that a recent study shows that applying this instrument resulted in the classification of a greater proportion of patients as being impaired in capacity than psychiatrists would have done on the basis of their clinical judgment. The authors take the view that from a moral and legal perspective it is preferable “that some patients, who in fact are incompetent, are misjudged to be competent, than that patients who are in fact competent are misjudged to be incompetent.”

Breden and Vollmann consider the narrow focus on cognitive abilities in competence assessment as ‘scientifically untenable.’ Therefore, an extension of this approach that includes components of the patient’s biographical and emotional context, personal construct systems, and sets of values, is sensible and a challenging task, which does not imply, however, that the MacCAT-T approach should be wholly rejected. In their view, an impulse may come from G.A. Kelly’s personal psychology approach, which focuses on the assessment and evaluation of personal construct systems and values. By interpreting the results of the cognitive based instruments in terms of the patient’s meaning-giving process, Breden and Vollmann think one might be able to close the gap between cognitive and non-cognitive approaches.

Tan and Fegert illustrate the complexities raised by capacity and competence in the field of child and adolescent psychiatry. These complexities are illustrated

by a case vignette of a patient suffering from anorexia nervosa (Case C: Natalie Smit). There is often a paradoxical relationship between the need for autonomy and participation and the capacity of children, and questions of capacity in treatment decisions in child and adolescent psychiatry can become crucial when there is conflict between the child's and the parent's interests.

The authors conclude that in child and adolescent psychiatry, there is often a discrepancy between the declared will of the patient and the covert or underlying wish of the patient. This discrepancy reflects the need in child and adolescent psychiatry to manage psychiatric disorder effectively while at the same time promoting the progressive development of autonomy which should be occurring during this developmental period.

From this perspective, Tan and Fegert criticize the current conception of capacity which is chiefly based on intellectual criteria of reasoning. Emotional and psychological maturity in their view is required to take responsibility for major or complex treatment decisions.

LEGAL CONTEXT

Because the assessment of mental capacity takes place in a legal context, the article by Nys, Welie, Garanis-Papadatos and Ploumpidis presents a legal overview of issues related to mental capacity in mental health care. The discriminatory effects of categorizing psychiatric patients into competent and incompetent, have urged lawyers, philosophers and health care professionals to seek a functional approach to capacity assessment. Dutch and English law have produced some guidelines concerning this issue. So far, however, most legal systems under investigation have concentrated on alternatives for informed consent by the patient in case of mental incapacity, notably substitute decision-making, intervention of a judge and advance directives. Nys et al. state that it is hard to judge how the law may further adapt to a more functional assessment of capacity, because the nature of law shows that legal reforms usually take place only when new methods have been accepted by the field, which presently is not yet the case.

CONCLUSION

With Higgs we may agree that new ethical and philosophical approaches to mental capacity and its assessment are being developed as 'work in progress.' These approaches deserve to receive critical attention because they deal with issues and topics which have been neglected or undervalued in the dominant cognitivist and rationalistic approaches to mental capacity. This new paradigm is still in its embryonic stage, although already the groundwork has been laid with respect to other issues in health care ethics (e.g. Lindemann Nelson and Lindemann Nelson, 1995).

The promise seems to be obvious, let alone by requiring those who are involved in mental capacity assessment to pay due attention to the broader context of what is at stake for the patient, the professional and others involved in decision making. Apart from the added value to the ongoing debate on mental capacity and its assessment, the new approaches of course also raise new questions. How can the hermeneutic approach help to distinguish between competent meaning making and incompetent meaning making? In what way can the narrative perspective be made productive in the assessment of mental capacity in everyday practice? And from the feminist perspective, how can the means be developed to enhance someone's competence? Ultimately, the merits of these approaches can only be judged in the practice of mental health care, by asking practitioners whether they provide them support in dealing responsibly with vulnerable patients whose rights and dignity are at stake.

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