

Changes in decision making capacity during illness: a review and case report with implications

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Summary

Mental health professionals in general hospital settings are frequently asked to provide consultative opinions about patients' capacity for medical decisions and self-care. Adult patients are assumed to be autonomous decision makers unless they have been determined to be incompetent through a judicial proceeding. In reality, however, clinical judgements of incapacity are often accorded the status of law. Treatment, when seen as in the patient's best interest, may proceed against the patient's explicit wishes. In addition, capacity decisions are often viewed as fixed, enduring states even though many medical conditions adversely affecting decisional skills are reversible.

Ms. Thornton, a 37-year-old woman, admitted for a ruptured cerebral aneurysm, underwent three capacity evaluations during her six week hospitalization. At the first two assessments separated by about two weeks, she demonstrated little understanding of her condition, treatment options, and likely outcomes with and without intervention.

At the third assessment, six weeks after admission, Ms. Thornton had regained adequate decisional capacity and was subsequently discharged. Clinicians conducting capacity evaluations in an era of brief hospitalization, with accompanying pressures to rapidly discharge patients, should include attention to both medical and psychiatric conditions, which when treated, lead to regained capacity.

Decision-Making Capacity / Competence / Ethical Issues

THEORETICAL AND RESEARCH BASIS

Consultation requests centering around patient competence are commonly received by general hospital psychologists and psychiatrists. Patients may be considered incapacitated when they exhibit "...functional deficits...judged to be sufficiently great that the person currently cannot meet the demands of a specific decision-making situation weighted in light of its potential consequence" [1]. Capacity questions may be raised about the patient's ability to live inde-

pendently, make medical decisions, care for children or dependent adults, manage finances, and enter into legally binding contracts. While the current case focuses primarily on medical decision-making, treating physicians also sought opinions about capacities for independent living and parenting.

Evaluations of patient's medical decision-making capacity are typically triggered by one of the following situations [2]: 1) The patient initiates the process of signing out of the hospital against medical advice; 2) There is concern about the patient's capacity to give informed consent for surgery, invasive tests, or other procedures; 3) There is concern about the patient's ability to take appropriate health precautions and comply with follow-up care; 4) The patient is refusing medical treatment for potentially life-threatening condition.

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Patients refusing treatment for a life-threatening medical condition raise both humanitarian and legal liability issues. Physicians may be held liable for not treating an incompetent patient refusing a procedure. Conversely, a provider may be held liable for battery if they perform a procedure on a competent patient refusing treatment [3]. Referral questions about patients' capacities for self-care and independent living are also common [2]. Personal care capacity includes the ability to make decisions about one's living situation — "Being able to determine whether the patient has a realistic appreciation of his own strengths and weaknesses such that he is able to make decisions about the amount of support and assistance he will require for daily living." [4]. Specific skills include hazard management, nutrition, hygiene, and activities of daily living. If the patient is unable to perform particular ADLs, they should exhibit some reasonable recognition of resources that they can use for assistance. When capacity fluctuates, a key issue is whether the patient can safely care for themselves during periods of poorest functioning.

Parenting capacity often becomes an issue in divorce-custody or child abuse cases. While there is no clear consensus about minimal capacity for child rearing, both cognitive and behavioural dimensions are important. Effective parenting includes basic child development knowledge, sensitivity to a child's unique needs, physical and psychological availability, ability to make simultaneously-determined judgements, and directly observable behavioural skills [5, 6].

Competence versus capacity

The hospital-based clinician frequently receives consultation requests phrased as "assess competence" or "is this patient competent to refuse surgery" or "patient refusing placement – need an assessment of competence." It is important to recognize that competence is a legal term. The psychological analogue of competence is capacity or decision-making ability. Despite this important distinction, most questions of capacity do not progress to court proceedings. Clinicians are often "de facto magistrates" whose clinical decisions are treated as legal judgements [7].

Legal standards typically indicate that a physician's or psychologist's determination of incapacity is required before a written advanced directive or durable power of attorney is implemented. In the general hospital, these determinations of incapacity typically occur routinely, informally, and without benefit of formal mental health evaluation. The treating physician, finding that the patient does not appear cognitively intact or capable of making reasonable decisions, automatically turns to next of kin for decisions about the patient's care – a practice supported by many state laws. Conversely, patients who agree with physicians' recommendations rarely have their capacity questioned.

Relationship between psychiatric conditions and capacity

While it is often assumed that a diagnosis of schizophrenia, organic brain dysfunction, degenerative dementia and/or mental retardation automatically limits a patient's ability to make decisions about their own and others welfare, this assumption is not supported by research or court rulings. A frequently cited case, *re: Yetter* [8] featured a patient with active symptomatic schizophrenia, who refused amputation of his gangrenous leg. While recognizing that without amputation, death was imminent, the patient expressed a desire to keep his body intact. Empirical studies have found that patients with schizophrenia are often capable of demonstrating adequate decisional skills for many basic health care decisions [3]. Similarly, the majority of subjects with mild mental retardation, and up to half of those with moderate mental retardation, were able to generate appropriate reasons for agreeing to a particular treatment [9]. Among psychiatric patients, there is evidence that educational remediation may improve capacity for medical decision-making. Lapid and colleagues [10] examined severely depressed patients' decisional skills regarding ECT using the McArthur Competence Assessment Tool-Treatment. The instrument reflects the four specific abilities used in the legal determination of competence to consent to treatment or research. Most hospitalized depressed patients were competent to make decisions about ECT. Patients whose competence

was questionable benefited from education and redisclosure of information [10].

Capacity as a continuum

Historically, capacity has been seen as an all-or-nothing phenomenon. Patients are either competent or incompetent to make decisions. If a patient was determined to be incompetent, it was assumed that they would not be able to make any significant life decisions. Substituted judgement, in the form of guardianship or durable power of attorney status, encompassed medical decisions but also financial management and other issues such as the ability to enter into contracts. By contrast, recent court rulings as well as ethical conceptualizations view capacity as domain specific. Within the domain of independent living, specific skills include taking medication on a regular basis, paying appropriate household bills, cooking, maintaining acceptable hygiene, and keeping the household free of significant health hazards. Even seemingly narrow dimensions are increasingly subdivided into specific skills. For example, a patient may have capacity to manage relatively small amounts of money (e.g. \$400 a month) but not be able to meaningfully participate in management of a larger portfolio including investment income. Additionally, when durable powers of attorney are enacted, it is increasingly common that different individuals be given distinct responsibilities. For example, while a patient's sister may make medical decisions on their behalf, their brother or close friend with financial skills may be the patient's financial durable power of attorney.

In the current case, several specific patient capacities were questioned. Initially, there were concerns about the patient's ability to make medical decisions. As the hospitalization progressed, questions were raised about the patient's ability to live independently as well as their parenting skills.

Temporal changes in capacity

Most discussions of capacity assessment present the evaluation as a solitary event in time with the assumption that capacity is a fixed characteristic. Patients are typically evaluated on one

occasion with little perceived need for reassessment [1]. However, it is well-known that both psychiatric and medical conditions impacting decision-making such as delirium or depression may be reversible, while other conditions such as schizophrenia include symptoms that may be controlled with pharmacotherapy. Schizophrenic patients' performance on decisional capacity tests improves as symptoms diminish [11]. Bostwick and Masterson [12] describe the use of flumazenil, a specific benzodiazepine antagonist, to temporarily reverse delirium and obtain informed consent. Within 30 minutes of receiving the drug, patients were able to meaningfully participate in decisions about their care and at least briefly, had their capacity restored before lapsing back into delirium.

Since capacity is a fluctuating state, patients determined to be incapacitated should be periodically reassessed [1]. However, while clinicians recognize that many reversible conditions may impact capacity for decision making, there are relatively few examples of regaining capacity described in the literature. The current case involved a patient whose capacity was evaluated at three different times during a six week hospital course. While the primary concern was the patient's ability to make medical decisions, her capacities for independent living and parenting were also questioned.

CASE STUDY

Ms. Thornton is a 33-year-old white female admitted for approximately 6 weeks to a general hospital. Ms. Thornton's hospitalization was precipitated by a subarachnoid haemorrhage which was, in turn, determined to be due to an anterior communicating aneurysm. The aneurysm was repaired during the course of the hospitalization. Ms. Thornton's capacity was raised as an issue by the medical team at three points: two days after admission, 10 days after neurosurgery, and one month later.

Presenting complaints

Ms. Thornton initially presented to the emergency department complaining of an "explod-

ing" headache and neck pain. She reported sudden onset of symptoms while arguing with her children's father. In addition, she described a sense of flushing in her face and blurred vision. Ms. Thornton left the emergency department after approximately 1 hour. Emergency department staff were very concerned and explained to the patient at the time that if she left the hospital against medical advice she would have a high probability of complications and possible death. However, the patient indicated that she needed a drink and abruptly left. Approximately 4 hours later, Ms. Thornton returned to the emergency department. At that time, a non-contrast CT of the head indicated a subarachnoid haemorrhage with blood present in the anterior intrahemispheric fissure around the circle of Willis and bilateral sylvian fissures. An angiogram was recommended to provide further information regarding the source of haemorrhage. The subarachnoid haemorrhage was determined to be due to an anterior communicating aneurysm and several days later, she underwent surgical repair of the aneurysm. Little past medical information was available at the time of her admission.

History

During the first month of her hospital course, Ms. Thornton had difficulty relating historical information. Near the end of her hospitalization, she indicated a past history of inpatient treatment for bipolar disorder in a state facility at age 26. She described at least one other psychiatric inpatient admission. Ms. Thornton stated that she was "hyper" at the time of her psychiatric hospital admissions but could not relate further details. She also had a history of alcohol abuse and apparently had become intoxicated the night of admission. Additionally, she exhibited evidence of borderline hypertension.

Ms. Thornton had three children ages 12, 8 and 4. She also was involved in a periodic conflictual relationship with the children's father.

Initial assessments

The psychologist was called into the intensive care unit during the second hospital day. At that time, Ms. Thornton was threatening to leave against medical advice.

The examiner followed a two-stage process in determining the patient's capacity [13]. Initially, basic cognitive skills such as orientation, attention, concentration and short-term recall were assessed with tasks such as serial 7's, digit span, and recall of four words at a five minute delay. The next part of the evaluation focused on the patient's decisional skills regarding her medical condition. At that time, the patient did not exhibit cognitive skills necessary for basic decision making. The examiner found her to be highly confused and agitated. Her attention and consciousness fluctuated considerably. She could not provide even a rudimentary description of her medical condition or recent symptoms. Ms. Thornton would not respond to many of the examiner's questions and after about 15 minutes asked the examiner to stop the interview. She indicated that she was feeling confused and could not respond to many of the questions posed to her.

Her hospital chart revealed that she was exhibiting bizarre behaviour, including kicking one of the resident physicians caring for her. She was also reportedly physically attacking nurses, taking other patient's wheelchairs and putting food such as pancakes and syrup on her bed sheets and eating directly from the sheets. Nursing staff suspected that she was taking hospital syringes. However, she would not allow staff to check her bag for these items.

At that time, the examiner concluded that the patient demonstrated little awareness of her condition or the risks of leaving the hospital against medical advice. This opinion was communicated to the ICU team caring for the patient and the patient remained in the hospital. This process exemplifies the psychologist as an "informal magistrate." No formal court hearing or external review of the psychologist's opinion occurred. However, the evaluation was used as the basis for detaining the patient involuntarily.

CONCEPTUAL BACKGROUND

Four Dimensional Clinical-Legal Model

Based upon review of case law as well as clinical literature, Grisso and Appelbaum [1] developed a framework to guide competence assessment, including four essential skills: (1) express-

ing a choice; (2) demonstrating an understanding of relevant information for decision-making; (3) appreciating information and applying it in one's own situation, as well as an appreciation of the consequences of the different treatment options; (4) active reasoning and weighing treatment options in a logical manner. This model's key advantage is that it can be readily translated to practical questions posed to patients. In this framework, the outcome, the decision itself, is of far less importance than the process by which it is reached.

The ability to express a choice is a "threshold" dimension [1]. Patients who are unable to express a clear choice are unlikely to be able to demonstrate the other three functional abilities. Clinically, expressing a choice requires the patient to reliably communicate a preference ("yes" or "no"), either verbally or non-verbally. Patients who reverse themselves often have questionable decisional capacity. Evaluating the patient's ability to understand relevant information can be determined by asking patients to explain in their own words information about their condition previously presented to them by the health care provider. Appreciating information refers to the ability to articulate personal consequences of therapeutic options including no treatment. The ability to reason, or actively weigh treatment options, is a higher standard typically assessed when patients refuse an effective treatment for a life-threatening condition. To meet this fourth standard, patients should be asked about how they reached a particular decision [1]. Any relevant factors (religious belief system, personal ethical values, family dynamics) should be probed if the patient does not spontaneously describe these issues [3].

Neuropsychological model

Marson [14] relates neuropsychological functions to five legal standards for specific competence: a) the capacity to evidence a treatment choice; b) to make a reasonable treatment choice; c) to appreciate the emotional, cognitive, and personal consequences of a treatment choice; d) to provide rational reasons for a treatment choice; and e) to understand treatment options [14]. These investigators have examined the underlying neuropsychological functions associat-

ed with these dimensions. For the first two levels, measures of simple auditory verbal comprehension and semantic knowledge (The Boston Naming Test) were key predictors of expert judgement of competence or incompetence. Patients demonstrating clear appreciation of the emotional and cognitive consequences of a treatment choice were found to demonstrate fairly intact semantic knowledge. For the two more challenging standards (rational reasons for treatment choice, understanding of treatment situation and choices), short-term recall and reasoning were most strongly associated with a physician's judgement of competence. Patients judged to be incompetent by experts were more likely to have impaired short-term recall as well as impaired conceptual skills. Neuropsychologically, semantic knowledge, simple reasoning ability, short-term memory, and receptive language appear to be the best predictors of decisional capacity [15].

Sliding standard method

In the sliding standard approach, the seriousness of the patient's condition with and without treatment is the principal factor determining the sophistication of reasoning required. Several authors [16, 17, 18, 19] argue that fixed standards cannot be applied to all capacity judgments. Instead, the proposed treatment's relative risk:benefit ratio leads to a sliding standard for evaluating patient's decisions. A patient agreeing to a low risk procedure such as a general physical does not typically require a detailed assessment of their judgement and reasoning. However, an elderly patient's refusal of a low risk therapy such as antibiotics for severe pneumonia carries significant risk requiring the patient to articulate a sophisticated rationale for a decision that could readily lead to their death. On this risk: benefit spectrum, agreement to a coronary artery bypass graft (CABG) surgery in a patient with significant occlusion of two coronary arteries, would occupy an intermediate position.

Impact of medical conditions

In Ms. Thornton's case, the anterior communicating aneurysm may contribute to impaired

memory and executive function deficits. Time and context may be confused and confabulation may occur to "fill in" cognitive gaps.

Personality changes often include disinhibition and inappropriate social behaviour [20]. Delusional misidentifications may also occur [21].

In the initial week Ms. Thornton's fluctuating consciousness, agitation and paranoid behaviour were suggestive of comorbid delirium. The combined CNS effects of alcohol withdrawal and the aneurysm likely contributed to this confusional state.

Course of illness and assessments

Approximately one week after admission, Ms. Thornton underwent clipping of the communicating arterial aneurysm. Postoperatively, she continued to exhibit cognitive deficits. She was placed on risperidone and fluoxetine as well as phenytoin as a seizure precaution. After approximately one week, the medical team determined that she was ready to be discharged. However, several of the physicians raised concerns about her capacity for self-care as well as for parenting her three children. A second evaluation was requested.

During the second assessment, Ms. Thornton cooperated for approximately 30 minutes. When asked directly, she was unable to provide her address, and was not completely oriented to time (she stated it was August when it was late October). She could not name the current President. Her immediate recall appeared to be grossly intact; however, when concentration demands increased slightly, she demonstrated more difficulty. On the Wechsler Memory Scale-Revised Logical Memory task, her score was at the first percentile for her age while her score on the Visual Reproduction memory task, (figural memory), was at the fourth percentile.

The patient's answers became increasingly tangential through the interview's course. During the second half of the evaluation, when asked specific questions about her medical condition, Ms. Thornton often responded with incoherent verbalizations unrelated to the questions. For example, when asked specifically about the reasons for her hospitalization, she responded "Everything is blending together; it has to do

with you." Later in the interview, she indicated that she was in the hospital "because I have kids." The patient demonstrated no recognition that she had a recent surgery. When asked directly about her capacity to care for her children, she stated that she would have one of the medical students from the hospital watch her children. Additionally Ms. Thornton began expressing paranoid delusions. For example, she referred to the nurses who were caring for her as "nurses dressed as doctors." She stated a nurse dressed as a doctor had threatened her sometime earlier.

The psychologist recommended that if Ms. Thornton were to be discharged from the hospital that she should be transferred to a nursing facility with 24-hour supervision. A further recommendation was that she have a guardian appointed on her behalf for medical decisions. Ms. Thornton remained hospitalized.

Approximately three weeks later, the psychologist was asked to see Ms. Thornton again. The medical team noted improvement in her mental status. While Ms. Thornton evidenced some pressured speech and tangentially, she could be readily redirected. Her thought processes appeared to be much more coherent than previously.

On the Wechsler Memory Scale, her verbal short-term recall had improved to the 20th percentile with her nonverbal figural recall at about the 45th percentile. On a concentration task (counting by 3's), she did request some cueing but performed significantly better than previously. During the interview, she described the events leading to her hospitalization in detail, in a manner consistent with her record. When asked specifically about her medical condition, Ms. Thornton stated she had a ruptured aneurysm. For the first time, she recognized that she had undergone brain surgery. She also described her emergency room visit in which she initially left against medical advice.

When asked about post-discharge plans, Ms. Thornton indicated that her medication would be prescribed by her primary care physician. While she could not provide the exact names of her medications, she explained she needed to take medicine regularly and typically multiple times per day for both seizures and pain. Ms. Thornton did report some concern about her

ability to care for her children, but stated that her sisters were going to be helping her.

Because of her greater coherence and level of cooperation, more information was obtained about her past history. Ms. Thornton indicated that she had first seen a psychiatrist at age 26. When asked about the reasons for that contact, she stated that she was "hyper." She described at least two prior psychiatric inpatient admissions and stated that she had been diagnosed "bipolar" in the past. At around that time, she described considerable energy and pronounced insomnia followed by episodes. She stated she had never been suicidal. Ms. Thornton did acknowledge a past history of alcohol abuse. She indicated that she understood that she would have to abstain from alcohol after discharge because of her medical condition.

At this third assessment, Ms. Thornton provided an appropriate, albeit somewhat limited, description of her medical condition. She also demonstrated an appreciation of her medical condition as well as the implications of her deficits for daily life (e.g., her children). For the first time, she recognized she needed ongoing medical care.

Complicating factors

As noted above, Ms. Thornton's history of significant psychiatric illness was not initially known. While alcohol had played a role in her initial choice to leave the emergency room against medical advice, the history of her alcohol use became better known during the third interview.

Another complicating factor was Ms. Thornton's responsibility for her children. While parenting capacity is typically evaluated differently than medical decision-making, basic cognitive skills such as reasoning, attention, concentration, and short-term memory are required for taking care of children. At the final assessment, Ms. Thornton did demonstrate some awareness that her capacity for childcare may be compromised.

Administrative considerations

Hospital treatment teams are under increased pressure to treat, or discharge patients rapidly.

Because of limited hospital days, patients may be declared competent or incompetent so that they can be quickly discharged or treated. These demands may lead to a subtle "agreement" between patients and staff for patients to sign out against medical advice if they are ambivalent about treatment [22]. It was noted in Umapathy study [22] that many "incompetent" patients who continued to refuse treatment were suddenly discharged from the hospital. Because of time pressures, hospital ethics committees and patient's families may not be consulted. General hospitals have recently reorganized roles so that social workers who were often the link between patients and their families, are reduced in number and services have been redefined. Social services have increasingly been directed towards case management and discharge planning rather than facilitating family involvement in patient care [22]. As a result, current requests for competency assessment may reflect physician's difficulties with patients who do not progress through a normal hospital course and for which disposition is needed.

Follow up

Ms. Thornton was referred to a psychiatrist for post-hospital treatment of Bipolar Disorder. She did not perceive her substance abuse history as problematic. Referrals were also made for neurology follow-up as well as for primary medical care. It is not known whether these visits occurred.

Treatment implications

Capacity assessments comprise up to 25% of general hospital consultation liaison referrals [23]. The growing geriatric population, widespread availability of life-sustaining therapies, increased medical complexity, decreased length of stay [22] and risk management concerns are likely to increase the number and intricacy of these requests.

Mrs. Thornton's hospital course illustrates several contemporary conflicts in capacity determination: time pressures in a general hospital, the

clinician's role as a "surrogate magistrate", and the reversibility of incapacity.

Ms. Thornton's initial evaluation was urgently requested to prevent her from leaving the hospital AMA. Time pressures in contemporary health care may lead to decisions that are not optimal for patient welfare. Consultants requesting assessment may subtly pressure consultants to render decisions that validate preconceptions [24]. While a determination of incapacity is probably the most commonly sought after opinion, discharge can be expedited by a judgment that a patient refusing therapy is cognitively intact. The emphasis on rapid disposition may be so extreme that patients who have been determined incapable of medical decisions are discharged without treatment [22].

Ms. Thornton, was never formally adjudicated as incompetent. However, hospital personnel treated her as if she had this legal status. Mental health professionals' judgements of incapacity are often perceived by hospital staff as legal rulings rather than clinical judgements [7]. While psychologists are ethically-bound to promote individual welfare, this principle may conflict with patients' legal right to due process if detained involuntarily.

Finally, Ms. Thornton's case emphasizes that capacity is not always stable but, may be a cognitive-emotional state impacted by psychiatric and medical illness. Clinicians performing capacity assessments should clearly document that their assessment refers only to decisional abilities at a specific point in time. The combination of pressure from treating physicians, managed care reviewers, together with the de facto impact of a clinical judgement of incapacity, may have immediate and long-term effects on a patient's treatment and subsequent placement.

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