

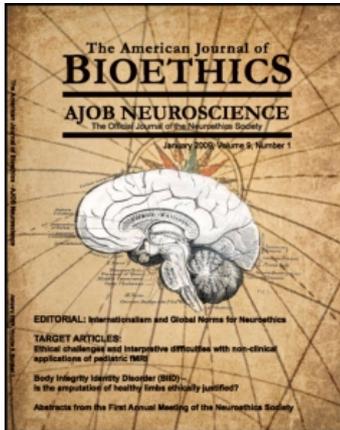
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Response to Commentaries on “Patient Autonomy for the Management of Chronic Conditions: A Two-Component Re-Conceptualization”

Aanand D. Naik ^{abc}; Carmel B. Dyer ^d; Mark E. Kunik ^{abc}; Laurence B. McCullough ^e

^a Houston Center for Quality of Care & Utilization Studies, ^b Michael E. DeBakey VA Medical Center, ^c Baylor College of Medicine, ^d University of Texas-Houston Medical School, ^e Center for Medical Ethics and Health Policy, Baylor College of Medicine,

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Correspondence

Response to Commentaries on “Patient Autonomy for the Management of Chronic Conditions: A Two-Component Re-Conceptualization”

Aanand D. Naik, Houston Center for Quality of Care & Utilization Studies; Michael E. DeBakey VA Medical Center; and Baylor College of Medicine

Carmel B. Dyer, University of Texas-Houston Medical School

Mark E. Kunik, Houston Center for Quality of Care & Utilization Studies; Michael E. DeBakey VA Medical Center; and Baylor College of Medicine

Laurence B. McCullough, Center for Medical Ethics and Health Policy, Baylor College of Medicine

The ethical concept of autonomy in modern bioethics has evolved with the healthcare system. The historical prominence of acute medical conditions and hospital-based medical care has strongly influenced the shape of bioethical concepts. Concepts of autonomy are not immune to this influence. The capacity to make informed decisions remains the central, often exclusive, focus of autonomy. In our target article (Naik et al. 2009) we describe how a one-component concept of autonomy that equates respect for informed decision making with respect for persons is ineffective and harmful in the contemporary predominance of complex and multiple chronic conditions. If the bioethical principle of respect for autonomy truly signifies “respect for persons,” then a second component of autonomy is essential within the context of the chronic disease era. A two-component re-conceptualization provides an expectation of collaborative patient-clinician deliberation to establish shared treatment goals and plans. Rather than being a luxury or the purview of exceptional doctoring, shared decision-making would be a tenet of all patient-clinician encounters involving complex or chronic illness care. Some commentators may view this approach to autonomy as common sense or even trite; however, the poor quality of chronic care and the low satisfaction with clinicians’ responsiveness and attitudes underscores the tangible adverse consequences of the one-component concept of autonomy (Committee on Quality of Healthcare in America, Institute of Medicine [IOM] 2001).

RESPONSE TO COMMENTARIES

Paul Appelbaum (2009) provides a series of nice examples of how arriving at a decision is not enough when evaluating capacity in many aspects of everyday functioning. We agree with his observation that performance of the particular tasks related to a decision is a long-understood aspect of capacity evaluation. This appreciation, however, has been lacking in medical decision-making due to the contexts of acute medical decisions as we describe in the target article (Naik et al. 2009).

It is important to draw a distinction between what Appelbaum (2009) describes as *performance* capacity and what we have defined as *executive* capacity. Executive capacity involves all aspects of treatment plan implementation. In our clinical practice, we can cite numerous examples of seniors with functional disabilities who may not be able to perform a task themselves, but have full capacity to formulate a plan of action, identify family members and social services they may need to execute their plan, and make adaptations along the way (with quick use of their cell phone) when tasks go unperformed. Executive capacity narrowly defined as performance alone could limit the autonomy of many capable adults with disabilities. We agree with Appelbaum (2009) that narrowing of executive capacity to performance alone would make measurement using neuropsychological tests highly suspect. While neuropsychological tests of executive cognitive functioning have more salience when executive capacity is framed broadly, we caution healthcare

Address correspondence to Aanand D. Naik, Houston Center for Quality of Care & Utilization Studies, Michael E. DeBakey VA Medical Center (152), 2002 Holcombe Blvd, Houston, TX 77030. E-mail: anaik@bcm.tmc.edu

and legal professionals that the results of neuropsychological tests alone are not equivalent to executive capacity.

Alan Jotkowitz and Yohanna Barth-Rogers (2009) and Antonio Casado da Rocha (2009) support our re-conceptualization of autonomy and, if anything, would seek to expand it further. Any meaningful exploration of executive capacity by patients and clinicians would invariably include family members, social supports, and cultural factors that help define treatment goals and plans. Autonomy defined by decisional capacity alone requires that clinicians elicit rational choices and decisions without exploring the meaning and social context of those decisions. Because chronic conditions impact normative and relational aspects of health and health care, a re-conceptualized autonomy could facilitate inclusion of caregivers in discussing the ends of healthcare and not just their role as means to health. The commentary by Casado da Rocha (2009) is consistent with our view here that executive capacity allows for an autonomy that “view patients as persons, people with stories of their own” (37) opening the door to cultural and relational variety in framing healthcare decisions.

Antonio Casado da Rocha (2009) references two recent articles in the bioethics literature that describe similar efforts to re-conceptualize autonomy, but both have important distinctions with our re-conceptualizations. The first by Anderson and Lux (2004) argues for a conception of autonomy that includes accurate self-assessment, of which executive function is but one component, but not for a two-component concept of autonomy such as we proposed. Moreover, it relies too heavily on neuropsychiatric measurement of executive cognitive functions in defining both decisional and executive capacities and does not allow for the fact that patient autonomy in chronic care is often iteratively understood as a treatment plan evolves. The second by Kukla (2005) creates a more robust “conscientious” autonomy by displacing roles and responsibilities to clinicians when patients have limited capacity (agency) to execute tasks. This is not an appeal to executive autonomy and a two-component model like ours. Worse, Kukla’s is the wrong corrective for overly complex and difficult chronic disease treatment plans. Our conceptualization of executive capacity requires that treatment goals be adapted to meet the capabilities of patients and that treatment plans may need to be customized and even curtailed to the circumstances of a patient’s life and capacity.

Using this existing literature, Casado da Rocha (2009) seeks to invoke “the right to give or withhold information freely and without pressure” as a distinct capacity within a comprehensive model of autonomy. We find it difficult to distinguish his invocation of information exchange from decisional capacity. However, we do believe that communicating and understanding health-related information play an important role when evaluating executive capacity. Any meaningful patient-clinician discussion of treatment goals and plans requires basic understanding by the patient. Health-related information that is overly complex, confusing, or designed at a level above a patient’s literacy cannot be

effectively utilized during deliberations of treatment planning. Inherent limitations in health literacy can effectively reduce executive capacity; however we believe that this issue is a system-wide problem impacting the overall quality of chronic illness care for even highly literate patients (IOM 2001). A re-conceptualization of autonomy to include executive capacity may raise clinicians’ awareness of the importance of information comprehension and transparency as a normative as well as quality issue in chronic care.

Joseph De Marco and Douglas Stewart (2009) make a curious claim that our re-conceptualization would limit informed consent and mandate that any patient with executive impairments would be incompetent as defined by probate courts. Our first corrective is to underscore that the re-conceptualization of autonomy applies only to the normative parameters of autonomy within the patient–clinician relationship. De Marco and Stewart forward an unsubstantiated assumption that autonomy and competence are synonymous, making their Venn diagram an incorrect representation of our conceptualization of autonomy. In our conceptualization, finding that a patient lacks executive capacity does not translate into a legal declaration of incompetence but rather a clinical and ethical imperative to revisit the treatment plan. We repeatedly cite Anderson and Funnel (2005) because of our strong belief in the relational nature of medical decisions and the importance of collaboratively ‘discovering’ the most appropriate individualized, treatment plan in the management of chronic conditions. Furthermore, it is unclear how a limitation in executive autonomy would imperil one’s right to informed consent or decisional capacity. In fact, a finding of impaired executive autonomy would instead necessitate a more extensive evaluation of decisional capacity to protect the rights of competent patients.

The example of Mrs. Townley is obtuse on many levels, especially since the physicians in the case used inappropriate methods to obtain a guardianship declaration. DeMarco and Stewart (2009) assume that our perspective is equivalent to that of the hospital-based physicians who encountered Mrs. Townley only during her medical decompensation and become frustrated with her “non-compliant behavior.” Quite the opposite, our re-conceptualization arises from experiences evaluating and providing primary care often in the homes of patients like Mrs. Townley. Our conceptualization would have noted that Mrs. Townley lacked executive capacity. We would then have worked with her to formulate a treatment plan consistent with her goal of living independently and to provide additional services and providers to support her limitations. If she were fully competent as DeMarco and Stewart suggest, this plan would likely be sufficient to improve Mrs. Townley’s condition and life goal of community living.

Another curious detail in Mrs. Townley’s case is the general presumption by DeMarco and Stewart (2009) that the patient had the capacity to make informed decisions. Verbally stating preferences is not the same thing as capacity to consent to treatment. The competence to judge capacity by

the hospital-based physicians, as well as their overall professionalism, is clearly in question. The threshold for even *considering* guardianship would only be crossed in Mrs. Townley's case if, after developing a shared treatment plan with her primary care provider, she repeatedly refused to allow home health providers into her home, created other obstacles to the treatment plan, and was a persistent danger to herself. In addition, a proper assessment of decision-making capacity as well as an evaluation for treatable conditions such as delirium and depression would then be necessary before involving any legal entity.

We evoke Anderson and Funnell (2005) not to justify deceptive guardianship claims or further physician authority. The process of exploring a patient's executive autonomy is exhaustive and consistent with the patient empowerment approach, which stresses the need to fully consider patient's goals and capabilities when developing and modifying shared treatment plans. DeMarco and Stewart (2009) are further concerned that executive autonomy would shift the source of noncompliance. In the re-conceptualized model of autonomy, "non-adherence and non-compliance are dysfunctional concepts" (Anderson and Funnell 2000). The claim of noncompliance often arises as a rational response of the one-component model (i.e., decisional autonomy is the whole of autonomy) to patients who do not execute their treatment plans or achieve treatment goals. In that model, these patients are either deemed to lack decisional capacity or must be autonomously noncompliant. Again, a patient with chronic diabetes who has difficulty implementing an overly ambitious treatment plan is likely to have some limitations in executive capacity. These limitations, especially those related to a situation as mundane as suboptimal glycemic control, cannot reasonably be construed to justify circumventing informed consent or precipitate a guardianship hearing. Treatments that do not reach clinical goals warrant an assessment of executive capacity and a reframed discussion of treatment goals and plans based on limitations in executive capacity, not a false choice between a judgment of the patient as lacking decision-making capacity and a judgment of the patient as noncompliant.

The problem with noncompliance in the current model of autonomy is that most noncompliant patients are assumed to be 'autonomously' noncompliant. This gives many clinicians a misleading, though convenient, rationale for not doing the difficult work of clarifying executive capacities and developing a shared treatment plan. Barbara Russell (2009) in her commentary is "puzzled" by these

patient-clinician encounters and describes such behavior by clinicians as negligent. But are clinicians negligent if they honor a patient's autonomous decision not to comply with therapy? Furthermore, clinicians do not routinely assess executive capacity. The executive component of autonomy is underappreciated and not given the same emphasis as decisional capacity even in chronic care settings. We do agree with Russell that what we propose is not a first and second autonomy as much as "patient autonomy writ large" with decisional and executive components. The great need for our target article is to draw attention and equal weight to the procedure elements of executive capacity and make the conclusion of autonomous noncompliance a diagnosis of exclusion. ■

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