Published in final edited form as:

Am J Bioeth. 2009 February ; 9(2): 23–30. doi:10.1080/15265160802654111.

Patient Autonomy for the Management of Chronic Conditions: A Two-Component Re-conceptualization

Aanand D. Naik, M.D.^{1,5,6}, Carmel B. Dyer, M.D.⁴, Mark E. Kunik, M.D., M.P.H.^{1,2,5,6,7}, and Laurence B. McCullough, Ph.D.^{1,2,3,5,6}

¹Houston Center for Quality of Care & Utilization Studies, Michael E. DeBakey VA Medical Center, Houston, Texas

²South Central Mental Illness Research, Education, and Clinical Center, Michael E. DeBakey VA Medical Center, Houston, Texas

³Center for Medical Ethics and Health Policy, Baylor College of Medicine, Houston, Texas

⁴Consortium for Research in Elder Self-Neglect, Geriatrics Program, Harris County Hospital District, University of Texas-Houston Medical School, Houston, Texas

⁵Baylor College of Medicine, Houston, Texas

⁶Alkek Department of Internal Medicine, Baylor College of Medicine, Houston, Texas

⁷Menninger Department of Psychiatry, Baylor College of Medicine, Houston, Texas

Abstract

The clinical application of the concept of patient autonomy has centered on the ability to deliberate and make treatment decisions (decisional autonomy) to the virtual exclusion of the capacity to execute the treatment plan (executive autonomy). However, the one-component concept of autonomy is problematic in the context of multiple chronic conditions. Adherence to complex treatments commonly breaks down when patients have functional, educational, and cognitive barriers that impair their capacity to plan, sequence, and carry out tasks associated with chronic care. The purpose of this article is to call for a two-component re-conceptualization of autonomy and to argue that the clinical assessment of capacity for patients with chronic conditions should be expanded to include both autonomous decision making and autonomous execution of the agreed-upon treatment plan. We explain how the concept of autonomy should be expanded to include both decisional and executive autonomy, describe the biopsychosocial correlates of the two-component concept of autonomy, and recommend diagnostic and treatment strategies to support patients with deficits in executive autonomy.

Keywords

Autonomy; Decision Making; Capacity; Executive Control Functions; Older Adults; Functional Assessment

Introduction

Medical education and the clinical training of medical students and residents occur primarily in the setting of the acute general hospital. The modern tertiary care hospital has a labor and delivery service and radiological and imaging services, but the bulk of the hospital consists of acute-care beds, increasingly intensive-care or critical-care beds in general specialties such as medicine or surgery, and in subspecialties such as cardiovascular and neurological surgery. Patients with chronic illnesses are seen in the hospital, but usually only when they have experienced an acute change in their condition that prompts hospital admission.

In parallel, most medical ethics teaching occurs in these tertiary care hospitals and so is skewed toward acute-care, high-drama cases. As a consequence, clinical judgments about patients' adherence to treatment are shaped by physicians' education and training rooted in the episodic, acute-care paradigm. In acute illness, patients' needs are urgent and finite and they seek care that is definitive and administered immediately (Wagner, Austin and Von Korff 1996; Anderson and Funnell 2005).

This acute care perspective of medical ethics pervades the bioethics literature. *Principles of Biomedical Ethics* is an acknowledged landmark in the field and in five editions has become the standard textbook for teaching bioethics. In the first edition Beauchamp and Childress take up the topic of refusal of treatment in their chapter on the principle of autonomy. In this section they make reference to cases presented in the appendix, including that of a pregnant woman who is a Jehovah's Witness who refused blood products for herself and her newborn child, who needed transfusion to prevent mental retardation and, possibly, also death. They also cite a case of a woman, also a Jehovah's Witness, who suffered massive blood loss, for whom a court order was successfully sought. The chapter concludes with a consideration of suicide and suicide prevention (Beauchamp and Childress 1979, 56–96). The chapter on respect for autonomy in the fifth edition makes reference to cases concerning organ transplantation, refusal of dialysis, and involuntary commitment of a patient who is a danger to himself (Beauchamp and Childress 2001, 57–112). Furthermore, the multiple editions of Pence's *Classic Cases in Medical Ethics*, the most thorough compendium of important cases in the field, are dominated by acute-care, high-drama cases. It is illustrative of the orientation of the field that, in this widely used textbook, Pence includes cases on provision of life-sustaining treatment for adults and children, physician-assisted suicide, in vitro fertilization, surrogate pregnancy, abortion, organ transplantation, and involuntary psychiatric hospitalization (Pence 1990, 1995, 2004, 2008).

This acute-care paradigm has a well-recognized and established perspective regarding the patient's role in medical decisions. The adult patient is presumed to have adequate capacity to understand and make decisions, i.e., to possess *decisional autonomy*, and therefore is presumed to have the capacity to participate in decisions about his or her medical care. The ethical principle of respect for autonomy requires that the patient with decisional autonomy be accorded authority over what will or will not be done regarding his or her medical care (Beauchamp and Childress 2001). From the perspective of decisional autonomy, behaviors or outcomes that are incongruent with the treatment plan are interpreted by clinicians as either an autonomous refusal of the physician's recommendations or the result of significant impairments in decisional autonomy that need to be assessed and responsibly managed.

Patients can and do electively choose to ignore physicians' recommendations, even in acute settings; and some may be in denial about their conditions and limit the effort needed to manage them. Physicians, reared in the acute-care paradigm, typically perceive non-adherence as a challenging but salient reflection of a patient's decisional autonomy (Anderson and Funnell 2005). Some patients with chronic conditions may articulate

understanding of the management plan and appear non-adherent when actually they are unable to implement the steps necessary to meet the treatment objectives. This is an underappreciated ethical challenge to the patient-physician relationship: the need for an expansion of the concept of patient autonomy to include, not only decisional autonomy, but also the patient's capacity to execute complex self-management tasks, i.e., *executive autonomy*. Patients with intact decisional autonomy may nevertheless have unappreciated physical, educational, and cognitive barriers that impair executive autonomy, i.e., their capacity to plan, sequence, and carry out tasks associated with the management of their chronic conditions. When faced with frequent readmissions for chronic disease exacerbations, adverse drug events, acute fluctuations in functional status, and other purported markers of non-adherence among otherwise motivated patients, physicians should expand the concept and clinical assessment of patient autonomy to include both autonomous decision-making capacity regarding treatment options, decisional autonomy, and autonomous execution of the agreed-upon treatment plan, executive autonomy.

The Two-Component Concept of Patient Autonomy

The concept of patient autonomy was developed in the context of acute care and rightly has centered on decisional autonomy, the patient's capacity to understand information and to make voluntary decisions. This is because, in acute care, the patient's role is to authorize intervention after a deliberative process. Clinicians largely perform the implementation or execution of that decision. The clinical benchmark for evaluating patient autonomy in this paradigm focuses on the patient's capacity to participate in the informed consent process, through which authorization is given or withheld (McCullough, Molinari and Workman 2001). After consenting, patients are only expected to comply with short-term therapy (e.g., 7 days of antibiotics), attend regular clinic appointments, or present on the day of surgery and not leave the hospital until discharged.

There is ample evidence of a consistent trend in the bioethics literature to equate autonomy with autonomous decision making, i.e., with decisional autonomy. A non-systematic review begins with the field's major reference work since 1978, the *Encyclopedia of Bioethics* (Reich 1978, 1995; Post 2004). The first edition (Reich 1978) did not have an entry on autonomy. The second edition's entry starts with:

The concept of autonomy in moral philosophy and bioethics recognizes the human capacity for self-determination, and puts forward a principle that the autonomy of persons ought to be respected (Miller 1995, 215).

The entry continues:

There are three elements to the psychological capacity of autonomy: agency, independence, and rationality. Agency is awareness of oneself as having desires and intentions and of acting on them. ... Independence is the absence of influences that so control what a person does that it cannot be said he or she wants to do it (Miller 1995, 215–216).

The third element, rationality, is equated to “rational decision making” (Miller 1995, 216). The most recent, third edition of the *Encyclopedia* includes the second-edition entry without updating.

Seminal works in clinical ethics also adopt accounts of autonomy that equate it with autonomous decision making. In their first edition Beauchamp and Childress wrote: “A person's autonomy is his or her independence, self-reliance, and self-contained ability to decide” (1979, 56). They explain the ethical principle of respect for autonomy as follows:

To respect autonomous agents is to recognize with due appreciation their own considered value judgments and outlooks even when it is believed that their judgments are mistaken. To respect them in this way is to acknowledge their right to their own views and the permissibility of their actions based on such beliefs (Beauchamp and Childress, 1979, 58).

The focus on decisional autonomy is even clearer by their fifth edition. They focus on “autonomous choice” (Beauchamp and Childress 2001, 58) and write: “We analyze autonomous action in terms of normal *choosers* who act (1) intentionally, (2) with understanding, and (3) without controlling influences that determine their action” (Beauchamp and Childress 2001, 59, emphasis added).

Grisso and Appelbaum have led the field in scholarly and clinical work on competence to consent. In their landmark book, they equate autonomy to self-determination and self-determination to “an interest in making autonomous decisions” (Grisso and Appelbaum 1998, 12). To exercise one’s autonomy is to choose autonomously. Autonomy and the “promotion of well-being” are the two values that underly competence (Grisso and Appelbaum 1998, 13), which, in turn, is explicated in terms of the patient’s ability to “*express a choice, ... understand the information relevant to treatment decision making, ... appreciate the significance of that information for one’s own situation, ... and to reason with relevant information so as to engage in a logical process of weighing treatment options*” (Grisso and Appelbaum 1998, 31, emphasis original). Their widely used MacCAT-T assessment tool is validated to assess the patient’s decisional capacity in research and clinical settings.

Jonsen, Siegler, and Winslade have in five editions produced the definitive textbook in clinical ethics. In their first edition, their four categories for analyzing the ethical dimensions of clinical cases included patients’ preferences:

Patient preferences are ethically significant because they make explicit the values of self-determination and personal autonomy that are deeply rooted in the ethics of our culture. Autonomy is the moral right to choose and follow one’s own plan of life and action (Jonsen, Siegler, and Winslade 1982, 53).

In the latest edition they essentially repeat the definition of respect for autonomy from the first edition as “the moral attitude that disposes one to refrain from interference with the autonomous beliefs and actions of others in pursuit of their goals” (Jonsen, Siegler, and Winslade 2002, 48). Respect for autonomy is implemented in the informed consent process, for which “decisional capacity” is required (Jonsen, Siegler, and Winslade 2002, 55).

It is striking that the dominant focus on decisional autonomy in the bioethics literature contrasts with the concept of autonomy articulated by Faden and Beauchamp (1986). They proposed a theory of autonomous action comprising three aspects: understanding, intentionality, and voluntariness (see Table 1). *Understanding* requires that a patient have sufficient knowledge of the situation and the available options or choices, as well as an appreciation of how these affect the patient on a personal level. To exhibit appreciation, a patient should demonstrate some rational process for weighing options and choices and their application to his or her circumstances. The requirement for understanding does not prohibit a patient from making unorthodox or even unreasonable choices as long as the criteria for understanding are fulfilled. *Intentionality* requires that actions are initiated and performed according to a patient’s goals and plan. At a minimum, patients should articulate their preferences and then settle on a course of action that implements their preferences. In the outpatient setting, intentionality also requires that patients participate in the development of the treatment plan and then execute the plan (Grimes, et al. 2000). The third aspect is *voluntariness* or the ability to act without substantially controlling influences. These include

external influences, such as those arising from coercion or manipulation, and internal impairments like hearing loss, pain or unreasonable fear that inhibit voluntary actions or compel involuntary actions.

The executive component of the concept of autonomy, introduced in this important contribution to medical ethics, has been greatly underappreciated over the subsequent 20 years. For example, a PUBMED search (available at http://www.ncbi.nlm.nih.gov/sites/entrez?holding=hamtmc_fft) of the recent bioethics literature for specific references to executive domains of autonomy using the terms: *consent* AND *autonomy* AND *executive function* produced only two citations. One citation was for a paper describing the neuroanatomical correlates of the conceptual domains proposed in Faden and Beauchamp's model of Informed Consent (Grimes, et al. 2000). The other was a systematic review of research on decision-making competence of cognitively impaired elderly that examined 32 papers concerned with "decision-making capacity," "decision-making competence," and "decision-making abilities" (Kim, Karlawish, and Caine 2002, 152).

The rationale for this comparative underappreciation may itself lie in the traditional focus on acute illnesses. *Intentionality* plays a much less significant role compared with *understanding* and *voluntariness* in established models of informed consent. The most commonly used clinical tools for confirming a patient's ability to give informed consent all extensively evaluate each domain of *understanding*, while *intentionality* is measured only as it relates to making and eliciting a single choice (Grisso, Appelbaum, and Hill-Fotouhi 1997; Marson, et al. 1995; Drane 1984). As described above, the intentional actions required of patients in acute care are circumscribed and time-limited. Furthermore, implementation and execution of a selected treatment are largely performed by clinicians in acute care.

The importance of the executive component of autonomy has become apparent with the shift from acute care, in which the patient authorizes and the clinical team executes a plan of care, to chronic care, in which the patient authorizes and then plays an essential role in executing the plan of care. Most recently, Lai and Karlawish have proposed a "new approach to assessing everyday decision-making capacity" (2007) that does make reference to executive function but not executive autonomy. Building on the work of Grisso and Appelbaum (1998), they propose a multidimensional, structured interview that adds to the MacCAT-T assessment of the patient's decision-making abilities. While they do call for assessment of executive function, they do so in the context of aiming at a "broader measure of ... [the patient's] cognitive deficits" (Lai and Karlawish 2007, 109). The goal is to assess "whether patients themselves are able to decide how much assistance they require in their current living situation" (Lai, Karlawish 2007, 109). Executive function is subsumed under the cognitive abilities for decision making, with little explicit reference to the dimensions of formulating, executing, and adapting implementation plans.

The nature and exercise of the patient's autonomy in the management of chronic conditions cannot be adequately conceptualized or clinically assessed by appealing to a concept of autonomy that includes only decisional autonomy. Chronic care models focus on the self-management of chronic conditions and adaptation to problems as they arise. In doing so, these approaches make an implicit appeal to an expanded concept of autonomy that we propose to make explicit, autonomous decision making (decisional autonomy) plus executive autonomy, the capacity to perform complex self-management tasks, especially those related to treatment planning and implementation.

Faden and Beauchamp's theory of autonomous action remains salient for the task of explicating this expanded concept of autonomy (see Table 2). In the context of the self-

management of chronic conditions, *intentionality* should be updated to include the patient's capacities to develop a treatment plan, to implement and monitor the plan, and to amend the treatment plan effectively in response to changing circumstances (Faden and Beauchamp 1986; Grimes, et al. 2000). Furthermore, *voluntariness* in the context of chronic illness should be updated to include freedom, not just from external coercion, but also from internal impairments that inhibit goal-directed or compel goal-antagonizing actions. Impairments of intentionality or voluntariness can manifest as impairments of executive autonomy that threaten the patient's ability to adhere to an agreed-upon treatment plan. Furthermore, impairments of executive autonomy can occur independently of or in conjunction with impairments of decisional autonomy.

This is seen commonly in vulnerable older adults with marked impairments of executive autonomy, likely arising from multiple deficits, who come to the attention of local adult protective agencies due to their inability to live safely and independently, i.e., geriatric syndrome of self-neglect (Naik, et al. 2006). These older individuals seemingly express preferences, but live in squalid environments often with untreated, advanced disease (Dyer, Pickens and Burnett 2007). These cases which are noted and reported by family members, caregivers and to a lesser extent health care professionals. Social services professionals, like many clinicians, evaluate expressed preferences and competency (decisional autonomy) without assessing executive autonomy. Important interventions to support individuals suffering from geriatric self-neglect can be unintentionally abandoned as a result of legal mandates arising from our limited concept of autonomy (Dyer 2005). Emerging evidence also links executive control functions to the development of disability and need for long-term care (Royall, Chiodo and Polk 2005). These findings have led some to suggest that determinations of one's capacity to choose to live independently in the community should include formal assessments of executive autonomy (Cooney, et al. 2004). Cases of self-neglect recognized and reported to protective service agencies by family members, caregivers and less often by health care professionals, represent an extreme end of the spectrum. However, the presence of decisional autonomy with lack of executive capacity is present in the routine care and management of persons with chronic disease.

Consider the case of Mrs. Brown (Box A) in the management of her chronic conditions. Any clinician who engages Mrs. Brown would find a patient adequately aware of the risks of her diabetes and eager to participate in the active treatment of her condition. Over several months, however, it has become clear that her capacity to perform her treatment plan is limited by her endogenous impairments, including diminished executive cognitive functions, and complicated by the demands of a rigorous treatment plan. In terms of the expanded, two-component concept of autonomy, she should be understood to exhibit deficits in *intentionality* and *voluntariness*, producing limitations in her executive autonomy that may be overlooked using assessments of decisional autonomy alone. Had Mrs. Brown's physician performed a screening evaluation for executive cognitive impairments after she was deemed non-adherent, appropriate changes to the treatment plan might have avoided further morbidity by simplifying the regimen to match the patient's executive capacities. Ongoing morbidity threatens her health and functional status and, therefore, her remaining autonomy.

Mrs. Brown's case highlights a persistent conceptual gap in how patients and clinicians plan and implement treatments for chronic diseases. Physicians focus almost exclusively on discussions of risk, expectations for treatment, and their own knowledge about best treatments. Physicians take on the responsibility for educating their patients and obtaining agreement regarding the scope and bounds of treatment. Since decision-making capacity is the primary basis for establishing patient autonomy, voluntary non-adherence is often the default assumption for patients' failure to comply with the treatment plan, especially when

that plan was collaboratively developed. Anderson and Funnell (2005) have described how this dysfunctional model of adherence in chronic care leads to the ethically flawed assumptions that patients' motivations are the source of treatment failure and that the best solution is for patients "to defer to the expertise (and authority derived from it) of clinicians and to follow the recommendations they have been given." Without a comprehensive conceptual and clinical appreciation for *both* decisional and executive autonomy in chronic care, this paradigm of non-adherence threatens the decisional autonomy and health outcomes of patients.

As the case of Mrs. Brown demonstrates, patients may be capable of engaging in robust deliberations about treatment goals and processes but physically or cognitively unable (and at times unaware of their inability) to participate in the implementation of the treatment plan. This incapacity is ethically and clinically significant because the patient's executive autonomy may be essential to effectively monitor and execute the treatment plan (Glasgow and Anderson 1999). Clinicians' awareness of these impairments, especially those linked to executive cognitive abilities, is underappreciated and not actively considered when developing treatment plans. In addition to the clinical realities of chronic care, the biological and psychological processes that govern behavior influence the two-component concept of patient autonomy.

Biopsychosocial Correlates of Decisional and Executive Autonomy

While the distinction between decisional and executive autonomy arises from the clinical and phenomenological observations of physicians and health providers, clinical scientists have described the neuropsychiatric and cognitive pathways that differentiate the processes of understanding, intentionality, and voluntariness (Workman et al. 2000; Royall et al. 2002). Understanding is heavily dependent on verbal and auditory communication and memory. Included are some functions related to attention; acquisition and processing of sensory data; and basic cognitive functions, including reasoning and aspects of judgment (Grimes, et al. 2000). In contrast, intentionality and voluntariness correlate much more strongly with *executive control functions*, comprising the cognitive skills needed to plan, initiate, sequence, monitor, and adapt complex goal-directed behaviors as well as the important connections among affect, motivation, and behavior (Grimes, et al. 2000; Workman, et al. 2000) controlled primarily by three frontal-lobe circuits (Royall, et al. 2002).

Recent studies have identified associations between impairments in executive control functions and treatment self-management, performance, and outcomes of chronic medical and psychiatric conditions (Royall, Cordes and Polk 1997; Allen, et al. 2003; Sateia 2003; Kuo, et al. 2005). These studies provide important empirical evidence linking the task requirements for chronic care and the capacity of patients to perform these tasks as distinct from the neurobehavioral correlates of decisional autonomy. Clinical studies of executive-control functions and their relationship with chronic disease outcomes and self-management behaviors offer compelling but preliminary evidence of this important link (Schillerstrom, Horton and Royall 2005). Additional research is needed to identify other factors that may correlate impairments in executive autonomy. Potential candidate factors include functional status, social support, health literacy, and co-morbid conditions such as depression. Some of these factors, illiteracy and depression, for example, are associated with impairments in decisional capacity, especially with severe presentations. In chronic care, even mild depressive symptoms may produce clinically and ethically significant impairments in executive autonomy that are often dismissed as examples of non-adherence. Improved understanding of these factors will aid the development and testing of interventions to support executive autonomy and thereby respect autonomy in chronic care.

Assessment and Management of Deficits in Executive Autonomy

In clinical assessments, decisional autonomy is treated as a threshold phenomenon: a judgment must be reached that either the patient has decisional capacity or does not. Access to treatment, participation in a trial, or even legal rights can be taken away if an individual lacks decisional autonomy. Executive autonomy, on the other hand, should be understood and clinically assessed along a clinical gradient rather than as a threshold phenomenon (in contrast to Faden and Beauchamp's account of intentionality as an either/or phenomenon). This distinction is important to avoid unnecessary infringements of patients' rights and simultaneously add a huge physical and financial burden on healthcare and social-services providers. The prevalence of impairments in executive autonomy may be significantly greater than that of decisional autonomy (Royall, et al. 2002).

Office-based screening tools, including well-validated measures of functional status (Applegate, Blass and Williams 1990; Pickens, et al. 2007) and physical performance (Studenski, et al. 2003), are useful tools for the assessment of executive autonomy. For example, cognitive decline in executive control functions can be evaluated using simple bedside tests, such as the Trail Making tests (Reitan and Wolfson 1995), the Frontal Assessment Battery (Dubois, et al. 2000), and the Executive Interview Test (Royall, Mahurin and Gray 1992). In addition, simple clinical tools to assess other important determinants of executive autonomy, such as health literacy (Bass, Wilson and Griffith 2003; Weiss, et al. 2005), depression (Yesavage, et al. 1982), and sensory impairment, are also readily available to augment the clinician's evaluation.

A physician who diagnoses significant impairments in executive autonomy, such as those that manifestly impair the implementation of a treatment plan, should proceed with the goal of supporting the patient's remaining autonomy (Molinari, McCollough and Workman 2004). For example, a visual aid and consultation with a diabetes educator for a diabetic patient who has trouble reading her glucose monitor and interpreting results can be used. Additionally, family, caregivers, and other community members can be enlisted to assist in the execution of the treatment plan by providing supervision and intervention to supplant deficits in executive autonomy.

Unlike decisional autonomy, even mild impairments in executive autonomy may be clinically significant and warrant the application of interventions to support a patient's participation in chronic care. The contribution of various social and clinical variables to executive autonomy adds additional complexity but also additional targets for clinical interventions. In the course of treatment for some patients, executive autonomy can become significantly impaired such that even extensive clinical interventions or social supports are ineffective. At this point along the continuum, individuals are at substantial risk for self-injury or harm to others. In these rare cases, a threshold is crossed; and interventions commonly used in cases of decisional incapacity, such as legal guardianship, are necessary. Furthermore, impairments may remain clinically silent until a change in health status occurs that exacerbates these impairments and threatens both decisional and executive autonomy. These examples suggest that a more dynamic, rather than static, conceptualization of executive and decisional autonomy is needed when approaching chronic disease care.

Conclusion

The one-component concept of patient autonomy as decisional autonomy is deeply rooted in the capacity to make informed choices regarding acute healthcare decisions. As physicians and patients co-manage chronic conditions and implement care plans, an expanded concept of patient autonomy that includes both decisional and executive autonomy is required. The

two-component conceptualization of patient autonomy adapts the Faden and Beauchamp approach, to fashion a model of autonomy that integrates decisional and executive domains into all assessments of a patient's capacity to make and implement decisions for her care.

When faced with frequent readmissions for disease exacerbations, adverse drug events, acute fluctuations in functional status, and other purported markers of non-adherence, physicians should consider whether the patient's executive autonomy to manage complex treatment plans and integrate them into their daily lives has become impaired, either independent of, or in synergy with, impairments of decisional autonomy. Judgments regarding non-adherence and other frustrations with patient motivation should be abandoned altogether. Instead, clinicians should focus on enhancing patients' autonomy and capacity in all facets of care. Effective treatment planning may be achieved through a dynamic, iterative process of identifying patients' limitations, tailoring appropriate interventions, and supplanting deficits of executive autonomy with adequate supports. This approach can occur in the chronic longitudinal setting as well as at discharge planning after an acute intervention. The two-component conceptualization of patient autonomy may have profound effects on the patient-clinician relationship and overall health outcomes.

Box A. Evaluating Decisional and Executive Autonomy: Mrs. Brown

Mrs. Brown is a 68-year-old widow with type 2 diabetes mellitus, congestive heart failure, osteoarthritis, and hypertension who lives alone in her home. She had been taking oral medications for diabetes but was switched to insulin-based therapy due to hyperglycemia despite her medications. She appeared willing to perform her diabetes treatments, including home glucose monitoring, after detailed discussions and training with her physician and a diabetes health educator. However, over time Mrs. Brown's physician begins to question her adherence to the treatment plan due to repeated office and emergency room visits for hyper- and hypoglycemia, shortness of breath and the development of a new foot ulcer.

Understanding

1. She is aware of the health consequences of diabetes and the importance of managing blood glucose to control diabetes.
2. She appreciates that her diabetes is advanced, with retinopathy and neuropathy, and that oral medications are no longer effective.
3. Mrs. Brown concedes the need to take insulin injections given the risk of serious morbidity from uncontrolled diabetes.

Intentionality

1. She expresses a preference for improved diabetes control and chooses an aggressive treatment plan using insulin injections.
2. Mrs. Brown constructs a treatment plan with her physician and diabetes educator that involves monitoring her daily blood glucose, aggressively adjusting her insulin, and regularly observing her feet.
3. Despite several months of treatment, Mrs. Brown's blood sugar remains poorly controlled. She has difficulty performing daily measurements, makes frequent errors in insulin dosing, and develops a new foot ulcer.

Voluntariness

1. Her decision to change treatment plans was free of coercion.

2. Mrs. Brown's impaired vision and limitations in executive cognitive functions may be internal inhibitors to performing her treatment plan.

Acknowledgments

This article is the result of work supported with resources and the use of facilities at the Houston Center for Quality of Care & Utilization Studies, Michael E. DeBakey Veterans Affairs Medical Center, the Consortium for Research in Elder Self-Neglect of Texas (NIH P20-RR020626), and a bioethics grant from the Greenwall Foundation. Dr. Naik is also supported by the National Institute of Aging (K23AG027144). The authors would like to thank Sonora Hudson for her careful review of a prior version of the manuscript.

References

- Allen SC, Jain M, Ragab S, Malik N. Acquisition and short-term retention of inhaler techniques require intact executive function in elderly subjects. *Age Ageing* 2003;32(3):299–302. [PubMed: 12720616]
- Anderson RM, Funnell MM. Patient empowerment: reflections on the challenge of fostering the adoption of a new paradigm. *Patient Education and Counseling* 2005;57(2):153–157. [PubMed: 15911187]
- Applegate WB, Blass JP, Williams TF. Instruments for the functional assessment of older patients. *New England Journal of Medicine* 1990;322(17):1207–1214. [PubMed: 2183053]
- Bass PF 3rd, Wilson JF, Griffith CH. A shortened instrument for literacy screening. *Journal of General Internal Medicine* 2003;18(12):1036–1038. [PubMed: 14687263]
- Beauchamp, TL.; Childress, JF. Principles of biomedical ethics. New York: Oxford University Press; 1979.
- Beauchamp, TL. Principles of biomedical ethics. 5th ed.. New York: Oxford University Press; 2001.
- Cooney LM Jr, Kennedy GJ, Hawkins KA, Hurme SB. Who can stay at home? Assessing the capacity to choose to live in the community. *Archives of Internal Medicine* 2004;164(4):357–360. [PubMed: 14980985]
- Drane JF. Competency to give an informed consent. A model for making clinical assessments. *Journal of the American Medical Association* 1984;252(7):925–927. [PubMed: 6748193]
- Dubois B, Slachevsky A, Litvan I, Pillon B. The FAB: a Frontal Assessment Battery at bedside. *Neurology* 2000;55(11):1621–1626. [PubMed: 11113214]
- Dyer CB. Neglect assessment in elderly persons. *Journals of Gerontology A: Biological Science and Medical Science* 2005;60(8):1000–1001.
- Dyer CB, Pickens S, Burnett J. Vulnerable elders: When it is no longer safe to live alone. *Journal of the American Medical Association* 2007;298(12):1448–1450. [PubMed: 17895463]
- Faden, RR.; Beauchamp, TL. A history and theory of informed consent. New York: Oxford University Press; 1986.
- Glasgow RE, Anderson RM. In diabetes care, moving from compliance to adherence is not enough. Something entirely different is needed. *Diabetes Care* 1999;22(12):2090–2092. [PubMed: 10587854]
- Grimes AL, McCullough LB, Kunik ME, Molinari V, Workman RH. Informed consent and neuroanatomic correlates of intentionality and voluntariness among psychiatric patients. *Psychiatric Services* 2000;51(12):1561–1567. [PubMed: 11097654]
- Grisso, T.; Appelbaum, PS. Assessing competence to consent to treatment: A guide for physicians and other health professionals. New York: Oxford University Press; 1998.
- Grisso T, Appelbaum PS, Hill-Fotouhi C. The MacCAT-T: a clinical tool to assess patients' capacities to make treatment decisions. *Psychiatric Services* 1997;48(11):1415–1419. [PubMed: 9355168]
- Jonsen, AR.; Siegler, M.; Winslade, WJ. Clinical ethics. New York: Macmillan; 1982.
- Jonsen, AR. Clinical ethics. 5th ed.. New York: McGraw-Hall; 2002.
- Kim SY, Karlawish JH, Caine ED. Current state of research on decision-making competence of cognitively impaired elderly persons. *American Journal of Geriatric Psychiatry* 2002;10(2):151–165. [PubMed: 11925276]

- Kuo HK, Jones RN, Milberg WP, Tennstedt S, Talbot L, Morris JN, et al. Effect of blood pressure and diabetes mellitus on cognitive and physical functions in older adults: a longitudinal analysis of the advanced cognitive training for independent and vital elderly cohort. *Journal of the American Geriatric Society* 2005;53(7):1154–1161.
- Lai JM, Karlawish J. Assessing the capacity to make everyday decisions: a guide for clinicians and an agenda for future research. *American Journal of Geriatric Psychiatry* 2007;15(2):101–111. [PubMed: 17272730]
- Marson DC, Ingram KK, Cody HA, Harrell LE LE. Assessing the competency of patients with Alzheimer's disease under different legal standards. A prototype instrument. *Archives of Neurology* 1995;52(10):949–954. [PubMed: 7575221]
- McCullough LB, Molinari V, Workman RH. Implications of impaired executive control functions for patient autonomy and surrogate decision making. *Journal of Clinical Ethics* 2001;12(4):397–405. [PubMed: 12026746]
- Miller, B. Autonomy. In: Reich, WT., editor. *Encyclopedia of bioethics*. 2nd ed.. New York: Macmillan; 1995. p. 215–220.
- Molinari V, McCullough LB, Workman RH. Geriatric assent. *Journal of Clinical Ethics* 2004;15(3):261–268. [PubMed: 15630869]
- Naik AD, Pickens S, Burnett J, Lai JM, Dyer CB. Assessing capacity in the setting of self-neglect: Development of a novel screening tool for decision-making capacity. *Journal of Elder Abuse and Neglect* 2006;8(4):79–92. [PubMed: 17972661]
- Pence, G. *Classic cases in medical ethics: Accounts of cases that have shaped medical ethics, with philosophical, legal, and historical backgrounds*. 2nd ed.. New York: McGraw-Hill; 1990.
- Pence, G. *Classic cases in medical ethics: Accounts of cases that have shaped medical ethics, with philosophical, legal, and historical backgrounds*. 2nd ed.. New York: McGraw-Hill; 1995.
- Pence, G. *Classic cases in medical ethics: Accounts of cases that have shaped medical ethics, with philosophical, legal, and historical backgrounds*. 3rd ed.. New York: McGraw-Hill; 2000.
- Pence, G. *Classic cases in medical ethics: Accounts of cases that have shaped medical ethics, with philosophical, legal, and historical backgrounds*. 4th ed.. New York: McGraw-Hill; 2004.
- Pence, G. *Classic cases in medical ethics: Accounts of cases that have shaped medical ethics, with philosophical, legal, and historical backgrounds*. 5th ed.. New York: McGraw-Hill; 2008.
- Pickens S, Naik AD, Burnett J, Kelly PA, Gleason M, Dyer CB. The utility of the KELS test in substantiated cases of elder self-neglect. *Journal of the American Academy of Nurse Practitioners* 2007;19(3):137–142. [PubMed: 17341281]
- Post, SG., editor. *Encyclopedia of bioethics*. 3rd ed.. New York: Thomson Gale; 2004.
- Reich, WT., editor. *Encyclopedia of bioethics*. New York: Macmillan; 1978. p. 1975
- Reich, WT., editor. *Encyclopedia of bioethics*. 2nd ed.. New York: Macmillan; 1995.
- Reitan RM, Wolfson D. Category-Test and Trail Making Test as measures of frontal lobe functions. *Clinical Neuropsychologist* 1995;9:50–56.
- Royall DR, Chiodo LK, Polk MJ. An empiric approach to level of care determinations: the importance of executive measures. *Journals of Gerontology A: Biological Science and Medical Science* 2005;60(8):1059–1064.
- Royall DR, Cordes J, Polk M. Executive control and the comprehension of medical information by elderly retirees. *Experimental Aging Research* 1997;23(4):301–313. [PubMed: 9352289]
- Royall DR, Lauterbach EC, Cummings JL, Reeve A, Rummans TA, Kaufer DI, et al. Executive control function: a review of its promise and challenges for clinical research. A report from the Committee on Research of the American Neuropsychiatric Association. *Journal Neuropsychiatry and Clinical Neuroscience* 2002;14(4):377–405.
- Royall DR, Mahurin RK, Gray KF. Bedside assessment of executive cognitive impairment: the executive interview. *Journal of the American Geriatrics Society* 1992;40(12):1221–1226. [PubMed: 1447438]
- Sateia MJ. Neuropsychological impairment and quality of life in obstructive sleep apnea. *Clinical Chest Medicine* 2003;24(2):249–259.

- Schillerstrom JE, Horton MS, Royall DR. The impact of medical illness on executive function. *Psychosomatics* 2005;46(6):508–516. [PubMed: 16288129]
- Studenski S, Perera S, Wallace D, Chandler JM, Duncan PW, Rooney E, et al. Physical performance measures in the clinical setting. *Journal of the American Geriatrics Society* 2003;51(3):314–322. [PubMed: 12588574]
- Wagner EH, Austin BT, Von Korff M. Organizing care for patients with chronic illness. *Milbank Quarterly* 1996;74(4):511–544. [PubMed: 8941260]
- Weiss BD, Mays MZ, Martz W, Castro KM, DeWalt DA, Pignone MP, et al. Quick assessment of literacy in primary care: the newest vital sign. *Annals of Family Medicine* 2005;3(6):514–522. [PubMed: 16338915]
- Workman RH Jr, McCullough LB, Molinari V, Kunik ME, Orengo C, Khalsa DK, et al. Clinical and ethical implications of impaired executive control functions for patient autonomy. *Psychiatric Services* 2000;51(3):359–363. [PubMed: 10686244]
- Yesavage JA, Brink TL, Rose TL, Lum O, Huang V, Adey M, et al. Development and validation of a geriatric depression screening scale: a preliminary report. *Journal Psychiatric Research* 1982;17(1):37–49.

Table 1**Faden and Beauchamp's Theory of Autonomous Action**

-
- 1) Understanding:** Actions based on understanding of the situation and choices
- a. Capacity to comprehend the circumstances and facts of a situation
 - b. Appreciation of the personal consequences of each choice and/or action
 - c. Evidence of a rational process for choosing one versus another option
- 2) Intentionality:** Actions are willed and performed according to one's plan
- a. Capacity to make and express preferences and choose a single option
 - b. Development of strategies and tactics for the execution of a choice
 - c. Performance of strategies and adaptations to changing circumstances
- 3) Voluntariness:** Ability to act without controlling influences
- a. Actions free of external coercion or manipulation
 - b. Actions not compelled or substantially inhibited by internal impairments
-

Table 2

Dimensions of Decisional and Executive Autonomy using Faden and Beauchamp's Theory of Autonomous Action

Decisional Autonomy	Executive Autonomy
<u>Understanding</u>	
Comprehension of circumstances and facts regarding a treatment decision	Comprehension of tasks required for treatment performance
Appreciation of personal consequences of a treatment decision	
Having a rational process for choosing one versus another option	
<u>Intentionality</u>	
Capacity to make and express a choice	
Development of a treatment plan	Identify strategies and surrogates (when appropriate) to implement plan
	Perform strategies and make adaptations to changing circumstances
<u>Voluntariness</u>	
Actions free of external coercion	Actions free of external coercion
	Actions not compelled or inhibited by internal impairments