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Medicine's Valuing of "Normal" Cognitive Ability

Julie M.G. Rogers, PhD, C. Christopher Hook, MD, and Rachel D. Havyer, MD

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Functionalists describe the role of medicine as maintaining the "normal" functioning of individuals and society [1]. Definitions of normal functioning, however, are subjective, determined by cultural and personal values. Medicine's values and the resulting explanatory model of disease do, in fact, promulgate a definition of normal functioning and, by extension, a version of "the good life." However, medicine's version of "the good life" may not reflect that of many of those it serves, causing a conflict that remains largely unrecognized. Herein we discuss how one of the most prominent values of the medical profession—intellectual ability [2]—contributes to that conflict. This valuing of intellectual ability constructs and projects onto patients an often misguided notion of "the good life," with far-reaching and unfortunate implications for those with cognitive or intellectual disabilities. We conclude with practical suggestions for how medical students, faculty, and practitioners can challenge biases that may be harming patients who have a different notion of "the good life."

Intellectual Ability and "The Good Life"

We surveyed two consecutive classes of first-year students at Mayo Medical School and asked them: "Would you be able to live a fulfilling life if you had a severe physical disability [or] severe cognitive disability?" Ninety-three of 95 students (98 percent) responded. Forty-nine students (53 percent) thought they could have a fulfilling life with a severe physical disability, but only 24 students (26 percent) thought they could have a fulfilling life with a severe cognitive disability (unpublished survey). In the resulting classroom discussion, the students recognized that their personal success and identity had been linked to their intellectual ability, making a cognitive impairment much more of a threat to their identities. They wondered if a similar survey of athletes would yield the opposite results.

Physicians are educated for many years and are rewarded for their intellect. It is not surprising that intellectual ability is a primary value held by academic physicians [2].

However, the notion that intellectual ability is an essential element of “the good life” is not necessarily congruent with the capably expressed [3] perceptions of the approximately 25 million people living with cognitive disabilities, intellectual disabilities, or both in the United States [4, 5]. While there is considerable diversity in findings of life satisfaction [6, 7] for people with cognitive and intellectual disabilities, some from sampled populations have expressed a high level of life satisfaction. For example, a national survey [8] reported that “99 percent of people with Down syndrome indicated that they were happy with their lives [and] 97 percent liked who they are” [9], a result that did not correlate with reported degree of learning difficulty [8]. Also, a recent survey of people with dementia found no correlation between a person’s level of cognitive impairment and reported quality of life [LINK: <http://journalofethics.ama-assn.org/2006/05/jdsc1-0605.html>] [10]. In fact, several clinical trials have shown significant increases in cognitive function in patients with dementia without changes in reported quality of life [11-14].

In studies showing that some people with a cognitive impairment experience a lower quality of life than those without cognitive impairments, the reasons cited for diminished quality of life more often include conditions like depression [15] or social factors like employment and relationship problems [6, 16, 17] than the cognitive impairment itself.

Historically, persons with cognitive and intellectual disabilities have lived with severe social stigma [18]. As they begin living in communities instead of institutions and obstacles to employment [19] and education [20] are addressed, social attitudes are also improving [21]. While this trend is also seen among medical professionals [22], change in medicine’s perception of intellectual and cognitive disability lags behind change in other professions’ attitudes. A study comparing members of four different helping professions who regularly interact with people with intellectual disabilities—physicians, psychologists, social workers, and special education teachers—found that physicians had significantly lower expectations and more pessimistic prognoses than surveyed members of all other professions [23].

Consequences of Medicine’s Valuing of Intellectual Ability

Medicine’s definition of normal intelligence is an intellectual quotient above 70. Similarly, a mental status exam score consistently below 26 suggests dementia [24]. Such measures of function are important to medicine because they are used to determine the need for and potential impact of interventions. Measures of life satisfaction or quality of life, on the other hand, are rarely considered. Of the numerous clinical trials that have investigated medical interventions for dementia, only a small percentage has included any measurements of patient life satisfaction [25]. As a direct consequence of the narrow design of this research, the targets of interventions are sometimes more controversial among patients and their families than those immersed in medical culture realize. For example, when parents of people with Down syndrome in Canada were asked

if they felt researchers should be trying to find a cure for Down syndrome, only 43 percent said “yes” [26]. Some research advancements hailed by the media as possible “cures” might be met by resistance from some parents of those with Down syndrome, a phenomenon described by one journalist as “Down syndrome soul searching” [27].

Many clinical ethical dilemmas arise from the intersection of intellectual and cognitive disability and medicine’s valuing of intellectual ability. For example, the medical literature discusses a “window of *opportunity*” to withdraw life-sustaining treatment for someone who is likely to survive an acute event with an intellectual or cognitive disability [28]—the term “opportunity” implying that death might be a preferable outcome. The medical literature contains few studies on the long-term quality of life of the people who survive acute events with disabilities (e.g., neonates who survive an intraventricular hemorrhage) [17, 29, 30]. Skotko, Levine, and Goldstein’s survey of people with Down syndrome found that 99 percent of those surveyed were happy with their lives [8], which would indicate that the assumption that a person’s interest is better served by dying than living with disability may be erroneous. And many of these respondents were born before the passage of the Baby Doe Law [31], when it was thought compassionate to allow a newborn with Down syndrome to die.

Such attitudes have real health consequences. People with intellectual disabilities meet most of the federal criteria for a “medically underserved population.” Two Surgeon General’s reports [32, 33] and a report from the National Council on Disabilities [34] describe decreased access and poorer-quality health care for people with intellectual disabilities. People in this population are less likely to receive preventive care [32], treatment for acute conditions [35], or desired care at the end of life [36]. The disparities have been partially attributed to overly negative attitudes on the part of clinicians [LINK: <http://journalofethics.ama-assn.org/2015/06/nlit2-1506.html>] [37, 38] about quality of life with a disability, which greatly influence proposed treatment plans [39, 40]. For example, it has been suggested that physicians undertake fewer smoking cessation discussions with patients who have intellectual disabilities than with patients who do not, because physicians assume that smoking provides some enjoyment in an otherwise unhappy life [41].

Not only is the health care provided to individuals with disabilities subpar, but their very self-concepts and their families’ perceptions of them can be affected. For example, a study found that people who were newly injured and interacting closely with medical staff absorbed negative attitudes about themselves [42]. Similarly, parents’ fear and anxiety were increased if medical staff chose to present what parents later perceived to be overly negative information at the time their children were diagnosed with intellectual disabilities [43]. This phenomenon is dangerous to a population that is overcoming social stigma and has only recently been afforded the same rights as other citizens [44]. Although pessimistic attitudes towards people with intellectual and cognitive disabilities

are prevalent in medicine, the impact of the problem on health is so great that it has been suggested that anyone prejudiced in this way should be excluded from the profession [38].

Suggestions for Current Medical Students, Medical Faculty, and Practitioners

Medicine's valuing of intellectual ability has negatively affected the care provided to people with intellectual and cognitive disabilities. But patients' accounts of their own experience show that the entire range of cognitive abilities, even those that fall well below a medically defined "normal," are compatible with a high or acceptable quality of life. To better serve patients with intellectual or cognitive disabilities, it is imperative that medicine challenge its own biases and recognize the harmful effect of imposing recommendations based on medicine's version of the "good life" on those who may hold different personal values. We provide a brief list of suggestions to move toward this goal.

1. *Teach about disability in medical school.* A national survey of medical students found that 81 percent were not receiving any clinical instruction on intellectual disabilities and 66 percent did not believe they received sufficient classroom instruction [45]. Furthermore, there are very few medical schools that have curricula addressing the lived experience of people with intellectual and cognitive disabilities, even though such curricula have the potential to improve attitudes toward these populations [46].
 - a. Individuals who have intellectual or cognitive disabilities should be involved in the design and implementation of this training [47, 48]. Their involvement would help challenge notions of "the good life" derived exclusively from medical culture and communicate the actual experiences of patients.
 - b. Make the value medicine places on intellect visible and a topic for discussion. Allow for reflection about how this value might manifest itself in the students' own decision making and potentially impact patient care.
 - c. Encourage premedical and medical students to gain experience working with people who have intellectual and cognitive disabilities through either volunteer or classroom activities. People who have relationships with people who have intellectual and cognitive disabilities are more likely to understand them [22, 49]. Discussion of student experiences with disability should be encouraged.

2. *Increase diversity* [LINK: <http://journalofethics.ama-assn.org/2015/04/msoc1-1504.html>] *in medical schools and, therefore, the medical profession.* Admit applicants who have disabilities and work toward improving their education. *Unnecessary barriers* [LINK: <http://journalofethics.ama-assn.org/2015/02/pfor2-1502.html>], such as overly rigid technical standards for admission and lack of the

accommodations that should be available according to the Americans with Disabilities Act, exist for medical school applicants who have disabilities [50]. Furthermore, there are notable discrepancies in medical education outcomes. Students without disabilities perform significantly better on the US Medical License Exam (USMLE) Steps 1 and 2 Clinical Knowledge, even with comparable academic and clinical performance [51], as well as on the Medical College Admissions Test (MCAT) [52]. The reasons for this discrepancy are poorly understood, and a failure to examine this problem perpetuates the stigma surrounding disability and the belief that intellectual “normalcy” is necessary for “the good life.”

3. *Treat the patient, not the impairment.*

- a. The dangers of adhering to “the golden rule,” or “treat others as you would like to be treated,” in a clinical setting have been described [53]. Physicians must recognize their own values and that these might be very different from those of their patients.
- b. Accordingly, if increasing cognitive function is an option, it should be discussed with the patient, but clinicians should not assume that increasing cognitive function is a goal.
- c. Clinicians should not assume that cognitive impairments necessarily decrease quality of life for every patient.
- d. If the patient describes a low quality of life, clinicians should not assume cognitive impairment is the cause but should explore depression and other mood disorders as well as social contributors to quality of life, like relationships and employment.

4. *Research the patient, not the impairment.*

- a. Interventions can only be useful to patients if they are in line with their own perception of “the good life.” Researchers should not assume that increased cognition is the only end goal that matters. Quality of life and social factors affecting people with intellectual and cognitive disabilities should also be studied [54].
- b. A good way to achieve this goal is to develop the aims of research programs with help from the community intended to benefit from the research.

We are urging a cultural change: not devaluing intelligence in medical professionals, but increasing awareness of medical culture and values and how they may differ from those of patients. All cultural change takes time and is challenging, but medical culture has been described as particularly difficult to change [55]. It is not impossible, however, and it is important that medicine does not, through its own unexplored values, perpetuate

inequalities for people with cognitive and/or intellectual disabilities as they attempt to overcome substantial historical stigma.

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Julie M.G. Rogers, PhD, is a fourth-year medical student at the Mayo Medical School in Rochester, Minnesota. She holds a PhD in biochemistry and molecular biophysics from the University of Pennsylvania and an MA in bioethics and health policy from Loyola University Chicago. Dr. Rogers is interested in disability ethics, especially as it pertains to intellectual disability and end-of-life care.

C. Christopher Hook, MD, is an associate professor; a consultant in hematology, internal medicine, and in the Special Coagulation Laboratory; and chair of the Enterprise Ethics Education Committee at the Mayo Clinic in Rochester, Minnesota. At the Mayo Clinic, he founded the Clinical Ethics Council and the ethics consultation service, among other clinical ethics services. He received his MD from the University of Illinois College of Medicine and did his postgraduate training in internal medicine, hematology, and medical oncology at the Mayo School of Graduate Medical Education.

Rachel D. Havyer, MD, is an assistant professor of medicine and a consultant in primary care internal medicine and palliative medicine at the Mayo Clinic in Rochester, Minnesota. She received her MD from the Mayo Medical School and did her postgraduate training in internal medicine at the Mayo School of Graduate Medical Education. Dr. Havyer is interested in improving the care and experience of patients and caregivers through scholarly work in palliative care and population health.

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