OPINIONS OF THE COUNCIL ON ETHICAL AND JUDICIAL AFFAIRS

The following opinions, 1–3, were presented by James E. Sabin, MD, Chair:

1. MEDICAL TOURISM

CEJA Opinion; no reference committee hearing.

HOUSE ACTION: FILED

See Opinion E-1.2.13

INTRODUCTION

At the 2018 Annual Meeting, the American Medical Association (AMA) House of Delegates adopted the recommendations of Council on Ethical and Judicial Affairs Report 3-A-18, "Medical Tourism." The Council issues this Opinion, which will appear in the next version of AMA PolicyFinder and the next print edition of the *Code of Medical Ethics*.

E-1.2.13 – Medical Tourism

Medical tourists travel to address what they deem to be unmet personal medical needs, prompted by issues of cost, timely access to services, higher quality of care or perceived superior services, or to access services that are not available in their country of residence. In many instances, patients travel on their own initiative, with or without consulting their physician, and with or without utilizing the services of commercial medical tourism companies. The care medical tourists seek may be elective procedures, medically necessary standard care, or care that is unapproved or legally or ethically prohibited in their home system.

Many medical tourists receive excellent care, but issues of safety and quality can loom large. Substandard surgical care, poor infection control, inadequate screening of blood products, and falsified or outdated medications in lower income settings of care can pose greater risks than patients would face at home. Medical tourists also face heightened travel-related risks. Patients who develop complications may need extensive follow-up care when they return home. They may pose public health risks to their home communities as well.

Medical tourism can leave home country physicians in problematic positions: Faced with the reality that medical tourists often need follow-up when they return, even if only to monitor the course of an uneventful recovery; confronted with the fact that returning medical tourists often do not have records of the procedures they underwent and the medications they received, or contact information for the foreign health care professionals who provided services, asked to make right what went wrong when patients experience complications as a result of medical travel, often having not been informed about, let alone part of the patient's decision to seek health care abroad. (IV, V, VI)

Physicians need to be aware of the implications of medical tourism for individual patients and the community.

Collectively, through their specialty societies and other professional organizations, physicians should:

- (a) Support collection of and access to outcomes data from medical tourists to enhance informed decision making.
- (b) Advocate for education for health care professionals about medical tourism.
- (c) Advocate for appropriate oversight of medical tourism and companies that facilitate it to protect patient safety and promote high quality care.
- (d) Advocate against policies that would require patients to accept care abroad as a condition of access to needed services.

Individually, physicians should:

- (e) Be alert to indications that a patient may be contemplating seeking care abroad and explore with the patient the individual's concerns and wishes about care.
- (f) Seek to familiarize themselves with issues in medical tourism to enable them to support informed decision making when patients approach them about getting care abroad.
- (g) Help patients understand the special nature of risk and limited likelihood of benefit when they desire an unapproved therapy. Physicians should help patients frame realistic goals for care and encourage a plan of care based on scientifically recognized interventions.
- (h) Advise patients who inform them in advance of a decision to seek care abroad whether the physician is or is not willing to provide follow-up care for the procedure(s), and refer the patient to other options for care.
- (i) Offer their best professional guidance about a patient's decision to become a medical tourist, just as they would any other decision about care. This includes being candid when they deem a decision to obtain specific care abroad not to be in the patient's best interests. Physicians should encourage patients who seek unapproved therapy to enroll in an appropriate clinical trial.
- (j) Physicians should respond compassionately when a patient who has undergone treatment abroad without the physician's prior knowledge seeks nonemergent follow-up care. Those who are reluctant to provide such care should carefully consider:
 - (i) the nature and duration of the patient-physician relationship;
 - (ii) the likely impact on the individual patient's well-being;
 - (iii) the burden declining to provide follow-up care may impose on fellow professionals;
 - (iv) the likely impact on the health and resources of the community.

Physicians who are unable or unwilling to provide care in these circumstances have a responsibility to refer the patient to appropriate services. (IV, V, VI)

2. EXPANDED ACCESS TO INVESTIGATIONAL THERAPIES

CEJA Opinion; no reference committee hearing.

HOUSE ACTION: FILED

See Opinion 7.3.10

INTRODUCTION

At the 2018 Annual Meeting, the American Medical Association (AMA) House of Delegates adopted the recommendations of Council on Ethical and Judicial Affairs Report 4-A-18, "Expanded Access to Investigational Therapies." The Council issues this Opinion, which will appear in the next version of AMA PolicyFinder and the next print edition of the *Code of Medical Ethics*.

E-7.3.10 – Expanded Access to Investigational Therapies

Physicians who care for patients with serious, life-threatening illness for whom standard therapies have failed, are unlikely to be effective, or do not exist should determine whether questions about access to investigational therapy through the U.S. Food and Drug Administration's "expanded access" program are likely to arise in their clinical practice. If so, physicians should familiarize themselves with the program to be better able to engage in shared decision making with patients.

When a patient requests expanded access to an investigational therapy, physicians should:

- (a) Assess the patient's individual clinical situation to determine whether an investigational therapy would be appropriate, including:
 - (i) whether there is a satisfactory alternative therapy available to diagnose, monitor, or treat the patient's disease or condition;
 - (ii) the nature of potential risks of the investigational therapy and whether those risks are not unreasonable in the context of the patient's disease or condition;
 - (iii) whether the potential benefit to the patient justifies the risks of the investigational therapy;
 - (iv) whether the patient meets inclusion criteria for an existing clinical trial of the investigational therapy.
- (b) As part of the informed consent process, advise the patient (or parent/guardian if the patient is a minor) that the investigational therapy has not yet been demonstrated to be effective in treating the patient's condition and may pose as yet unknown risks. Physicians should explain the importance of clinical trials, encourage patients who meet inclusion criteria to participate in an existing trial rather than seek access to investigational therapy through the FDA expanded access program, and direct patients who wish to participate in research to appropriate resources.
- (c) Decline to support an application for expanded access to an investigational therapy when:
 - (i) the physician judges the treatment with the investigational therapy not to be in the patient's best interest, and explain why; or
 - (ii) the physician does not have appropriate resources and ability to safely supervise the patient's care under expanded access.

In such cases, physicians should refer the patient to another physician with whom to discuss possible application for expanded access.

- (d) Discuss the implications of expanded access for the patient and family and help them form realistic expectations about what it will mean to be treated with the investigational therapy outside a clinical trial. Physicians should alert patients:
 - (i) to the possibility of financial or other responsibilities associated with receiving an investigational therapy through expanded access;
 - (ii) to the lack of infrastructure to systematically monitor and evaluate the effects of the investigational therapy outside a clinical trial;
 - (iii) that they need information about how to contact the manufacturer for guidance if they seek emergency care from a health care professional who is not affiliated with a clinical trial of the investigational therapy;
 - (iv) that the physician has a responsibility to collect and share clinical information about the patient's course of treatment with the investigational therapy, as well as to report any adverse events that may occur over the course of treatment;
 - (v) to the conditions under which the physician would recommend stopping treatment with the investigational therapy. (V,VI)

3. MERGERS OF SECULAR AND RELIGIOUSLY AFFILIATED HEALTH CARE INSTITUTIONS

CEJA Opinion; no reference committee hearing.

HOUSE ACTION: FILED

See Opinion 11.2.6

INTRODUCTION

At the 2018 Annual Meeting, the American Medical Association (AMA) House of Delegates adopted the recommendations of Council on Ethical and Judicial Affairs Report 2-A-18, "Mergers of Secular and Religiously Affiliated Health Care Institutions." The Council issues this Opinion, which will appear in the next version of AMA PolicyFinder and the next print edition of the *Code of Medical Ethics*.

E-11.2.6 – Mergers of Secular and Religiously Affiliated Health Care Institutions

The merger of secular health care institutions and those affiliated with a faith tradition can benefit patients and communities by sustaining the ability to provide a continuum of care locally in the face of financial and other pressures. Yet consolidation among health care institutions with diverging value commitments and missions may also result in limiting what services are available. Consolidation can be a source of tension for the physicians and other health care professionals who are employed by or affiliated with the consolidated health care entity.

Protecting the community that the institution serves as well as the integrity of the institution, the physicians and other professionals who practice in association with it, is an essential, but challenging responsibility.

Physician-leaders within institutions that have or are contemplating a merger of secular and faith-based institutions should:

- (a) Seek input from stakeholders to inform decisions to help ensure that after a consolidation the same breadth of services and care previously offered will continue to be available to the community.
- (b) Be transparent about the values and mission that will guide the consolidated entity and proactively communicate to stakeholders, including prospective patients, physicians, staff, and civic leaders, how this will affect patient care and access to services.
- (c) Negotiate contractual issues of governance, management, financing, and personnel that will respect the diversity of values within the community and at minimum that the same breadth of services and care remain available to the community.
- (d) Recognize that physicians' primary obligation is to their patients. Physician-leaders in consolidated health systems should provide avenues for meaningful appeal and advocacy to enable associated physicians to respond to the unique needs of individual patients.
- (e) Establish mechanisms to monitor the effect of new institutional arrangements on patient care and well-being and the opportunity of participating clinicians to uphold professional norms, both to identify and address adverse consequences and to identify and disseminate positive outcomes.

Individual physicians associated with secular and faith-based institutions that have or propose to consolidate should:

- (f) Work to hold leaders accountable to meeting conditions for professionalism within the institution.
- (g) Advocate for solutions when there is ongoing disagreement about services or arrangements for care. (VII, VIII, IX)

REPORTS OF THE COUNCIL ON ETHICAL AND JUDICIAL AFFAIRS

The following reports, 1–5, were presented by James E. Sabin, MD, Chair:

1. COMPETENCE, SELF-ASSESSMENT, SELF-AWARENESS

Reference committee hearing: see report of Reference Committee on Amendments to Constitution and Bylaws.

HOUSE ACTION: REFERRED

The expectation that physicians will provide competent care is central to medicine. This expectation shaped the founding mission of the American Medical Association (AMA) and runs throughout the AMA *Code of Medical Ethics* [1-4]. It undergirds professional autonomy and the privilege of self-regulation granted to medicine by society [5]. The profession promises that practitioners will have the knowledge, skills, and characteristics to practice safely and that the profession as a whole and its individual members will hold themselves accountable to identify and address lapses [6-9].

Yet despite the centrality of competence to professionalism, the *Code* has not hitherto examined what the commitment to competence means as an ethical responsibility for individual physicians in day-to-day practice. This report by the Council on Ethical and Judicial Affairs (CEJA) explores this topic to develop ethics guidance for physicians.

DEFINING COMPETENCE

A caveat is in order. Various bodies in medicine undertake point-in-time, cross-sectional assessments of physicians' technical knowledge and skills. However, this report is not concerned with matters of technical proficiency assessed by medical schools and residency programs, specialty boards (for purposes of certification), or hospital and other health care organizations (e.g., for privileging and credentialing). Such matters lie outside the Council's purview.

The ethical responsibility of competence encompasses more than knowledge and skill. It requires physicians to understand that as a practical matter in the care of actual patients, competence is fluid and dependent on context. Importantly, the ethical responsibility of competence requires that physicians at all stages of their professional lives be able to recognize when they are and when they are not able to provide appropriate care for the patient in front of them or the patients in their practice as a whole. For purposes of this analysis, competence is understood as "the habitual and judicious use of communication, knowledge, technical skills, clinical reasoning, emotions, values, and reflection in daily practice for the benefit of the individual and the community being served" and as "developmental, impermanent, and context dependent" [10].

Moreover, the Council is keenly aware that technical proficiency evolves over time—what is expected of physicians just entering practice is not exactly the same as what is expected of mid-career physicians or physicians who are changing or re-entering practice or transitioning out of active practice to other roles. Each phase of a medical career, from medical school through retirement, carries its own implications for what a physician should know and be able to do to practice safely and to maintain effective relationships with patients and with colleagues.

The concept that informs this report differs as well from the narrower definition of competence as the knowledge and skills an individual has to do a job. Rather, this report explores a broader notion of competence that encompasses deeper aspects of wisdom, judgment and practice that enable physicians to assure patients, the public, and the profession that they provide safe, high quality care moment to moment over the course of a professional lifetime.

FROM SELF-ASSESSMENT TO "INFORMED" SELF-ASSESSMENT

Health care institutions and the medical profession as a whole take responsibility to regulate physicians through credentialing and privileging, routinely testing knowledge (maintenance of certification, requirements for continuing education, etc.) and, when needed, taking disciplinary action against physicians who fail to meet expectations for competent, professional practice. However, the better part of the responsibility to maintain competence rests with physicians' "individual capacity, as clinicians, to self-assess [their] strengths, deficiencies, and learning needs to maintain a level of competence commensurate with [their] clinical roles" [11].

Self-assessment has thus become "integral to many appraisal systems and has been espoused as an important aspect of personal professional behavior by several regulatory bodies and those developing learning outcomes for students" [12]. Undergraduate and graduate medical education programs regularly use self-assessment along with third-party evaluations to ensure that trainees are acquiring the knowledge and skills necessary for competent practice [5,10,13-16].

Yet how accurately physicians assess their own performance is open to question. Research to date suggests that there is poor correlation between how physicians rate themselves and how others rate them [5,12,13]. Various studies among health professionals have concluded that clinicians and trainees tend to assess their peers' performance more accurately than they do their own; several have found that poor performers (e.g., those in the bottom quartile) tend to over-estimate their abilities while high performers (e.g., those in the top quartile), tend to under-estimate themselves [5,12,17].

The available findings suggest that self-assessment involves an interplay of factors that can be complicated by lack of insight or of metacognitive skill, that is, ability to be self-observant in the moment. Similarly, personal characteristics (e.g., gender, ethnicity, or cultural background) and the impact of external factors (e.g., the purpose of self-assessment or whether it is designed to assess practical skills or theoretical knowledge) can all affect self-assessment [12,18]. The published literature also indicates that interventions intended to enhance self-assessment may seek different goals—improving the accuracy of self-assessors' perceptions of their learning needs, promoting appropriate change in learning activities, or improving clinical practice or patient outcomes [12].

Self-assessment tools alone are not sufficient measures of physicians' ability to provide safe, high quality care. Feedback from third parties is essential—or as one researcher has observed, "The road to self-knowledge may run through other people" [19]. However, physicians are often wary of assessment. They have indicated that while they want feedback, they are not sure how to use information that is not congruent with their self-appraisals [20]. Physicians can be hesitant to seek feedback for fear of looking incompetent or exposing possible deficiencies or out of concern that soliciting feedback could adversely affect their relationships with those whom they approach [20]. They may also question the accuracy and credibility of the assessment process and the data it generates [21].

To be effective, feedback must be valued both by those being assessed and by those offering assessment [14]. When there is tension between the stated goals of assessment and the implicit culture of the health care organization or institution, assessment programs can too readily devolve into an activity undertaken primarily to satisfy administrators that rarely improves patient care [20]. Feedback mechanisms should be appropriate to the skills being assessed—multi-source reviews ("360° reviews"), for example, are generally better suited to providing feedback on communication and interpersonal skills than on technical knowledge or skills—and easy for evaluators to understand and use [14]. High quality feedback will come from multiple sources; be specific and focus on key elements of the ability being assessed; address behaviors rather than personality or personal characteristics; and "provide both positive comments to reinforce good behavior and constructive comments with action items to address deficiencies" [22]. Beyond such formal mechanisms, physicians should welcome and seek out informal input from colleagues. They should be willing to offer timely comments to colleagues as well.

One study among physicians and physicians in training found that participants used a dynamic, multidimensional process to assess their own abilities. Under this process of what researchers identified as "informed self-assessment," participants interpreted and responded to multiple types of information, such as cognitive and affective data, from both formal and informal sources [23]. Participants described "critically reflecting 'in action,' that is, during an activity or throughout the day:"

I think we do a lot of it without thinking of it as reflection. We do it every day when we look at a patient's chart. You look back and see the last visit, "What did I do, or should I have done something different?" I mean that's reflection, but yet I wouldn't have thought of that as self-assessment or self-reflection, but we do it dozens of times a day [23].

EXPERTISE & EXPERT JUDGMENT

On this broad understanding of competence, physicians' thought processes are as important as their knowledge base or technical skills. Thus, understanding competence requires understanding something of the nature of expertise and processes of expert reasoning, themselves topics of ongoing exploration [24,25,26,27]. Prevailing theory distinguishes

"fast" from "slow" thinking; that is, reflexive, intuitive processes that require minimal cognitive resources versus deliberate, analytical processes that require more conscious effort [26]. Some scholars take expertise to involve "fast" processes, and specifically decision making that involves automatic, nonanalytic resources acquired through experience [24]. Others argue that expertise consists in using "slow," effortful, analytic processes to address problems [24]. A more integrative view argues that expertise resides in being able to transition between intuitive and analytical processes as circumstances require. On this account, experts use automatic resources to free up cognitive capacity so that they maintain awareness of the environment ("situational awareness") and can determine when to shift to effortful processes [24].

Expert judgment is the ability "to respond effectively in the moment to the limits of [one's] automatic resources and to transition appropriately to a greater reliance on effortful processes when needed" [24], a practice described as "slowing down." Knowing when to slow down and be reflective has been demonstrated to improve diagnostic accuracy and other outcomes [26]. To respond to the unexpected events that often arise in a clinical situation, the physician must "vigilantly monitor relevant environmental cues" and use these as signals to slow down, to transition into a more effortful state [25]. This can happen, for example, when a surgeon confronts an unexpected tumor or anatomical anomaly during a procedure. "Slowing down when you should" serves as a critical marker for intraoperative surgical judgment [24].

INFLUENCES ON CLINICAL REASONING

Clinical reasoning is a complex endeavor. Physicians' capabilities develop through education, training, and experiences that provide tools with which to shape their clinical reasoning. Every physician arrives at a diagnosis and treatment plan for an individual in ways that may align with or differ from the analytical and investigative processes of their colleagues in innumerable ways. When something goes wrong in the clinic, it can be difficult to discern why. Nonetheless, all physicians are open to certain common pitfalls in reasoning, including relying unduly on heuristics and habits of perception, and succumbing to overconfidence.

Heuristics

Physicians often use various heuristics—i.e., cognitive short cuts—to aid decision making. While heuristics can be useful tools to help physicians identify and categorize relevant information, these time-saving devices can also derail decision making. For example, a physician may mistakenly assume that "something that seems similar to other things in a certain category is itself a member of that category" (the representative heuristic) [28], and fail to diagnose a serious health problem. Imagine a case in which a patient presents with symptoms of a possible heart attack or a stroke that the physician proceeds to discount as stress or intoxication once the physician learns that the patient is going through a divorce or smells alcohol on the patient's breath. Or a physician may miscalculate the likelihood of a disease or injury occurring by placing too much weight "on examples of things that come to mind easily, . . . because they are easily remembered or recently encountered" (the availability heuristic) [28]. For example, amidst heavy media coverage of an outbreak of highly infectious disease thousands of miles away in a remote part of the world, a physician seeing a patient with symptoms of what is actually a more commonplace illness may misdiagnose (or over diagnose) the exotic condition because that is what is top of mind.

Clinical reasoning can be derailed by other common cognitive missteps as well. These can include misperceiving a coincidental relationship as a causal relationship (illusory bias), or the tendency to remember information transferred at the beginning (or end) of an exchange but not information transferred in the middle (primary or recency bias) [28,29,30].

Habits of Perception

Like every other person, physicians can also find themselves prone to explicit (conscious) or implicit (unconscious) habits of perception or biases. Physicians may allow unquestioned assumptions based on a patient's race or ethnicity, gender, socioeconomic status, or health behavior, among other features, to shape how they perceive the patient and how they engage with, evaluate and treat the individual. Basing one's interactions with a patient on pre-existing expectations or stereotypes demeans the patient, undermines the patient's relationship with the physician and the health care system, and can result in significant health disparities across entire communities [31]. This is of particular concern for patients who are members of minority and historically disadvantaged populations [31]. Physicians may fall victim to the tendency to seek out information that confirms established expectations or dismiss contradicting

information that does not fit into predetermined beliefs (confirmatory bias) [28]. These often inadvertent thought processes can result in a physician pursuing an incorrect line of questioning or testing that then leads to a misdiagnosis or the wrong treatment.

No matter how well a patient may seem to fit a stereotype, it is imperative that the physician look beyond categories and assumptions to investigate openly the health issues experienced by the patient. Although all human beings exhibit both conscious and unconscious habits of perception, physicians must remain vigilant in not allowing preconceived or unexamined assumptions to influence their medical practice.

Overconfidence

Finally, another obstacle to strong clinical reasoning that physicians may encounter is overconfidence. Despite their extensive training, physicians, like all people, are poor at identifying the gaps in their knowledge [28,30]. Physicians may consider their skills to be excellent, when, in fact, their peers have identified areas for improvement [30]. Overconfidence in one's abilities can lead to suboptimal care for a patient, be it through mismanaging resources, failing to consider the advice of others, or not acknowledging one's limits [28,30].

To avoid falling into such traps, physicians must recognize that many factors can and will influence their clinical decisions [28]. They need to be aware of the information they do and do not have and they need to acknowledge that many factors can and will influence their judgment. They should keep in mind the likelihood of diseases and conditions and take the time to distinguish information that is truly essential to sound clinical judgment from the wealth of possibly relevant information available about a patient. They should consider reasons their decisions may be wrong and seek alternatives, as well as seek to disprove rather than confirm their hypotheses [28]. And they should be sensitive to the ways in which assumptions may color their reasoning and not allow expectations to govern their interactions with patients.

Shortcomings can be an opportunity for growth in medicine, as in any other field. By becoming aware of areas in which their skills are not at their strongest and seeking additional education or consulting with colleagues, physicians can enhance their practice and best serve their patients.

Physicians' ability to practice safely can be affected by their own health, of course. The *Code of Medical Ethics* addresses such situations in guidance on physicians' health and wellness ($\underline{E-9.3.1}$) and their responsibilities to impaired colleagues ($\underline{E-9.3.2}$).

FROM INFORMED SELF-ASSESSMENT TO SELF-AWARENESS

Recognizing that many factors affect clinical reasoning and that self-assessment as traditionally conceived has significant shortcomings, several scholars have argued that a different understanding of self-assessment is needed, along with a different conceptualization of its role in a self-regulating profession [32]. Self-assessment, it is suggested, is a mechanism for identifying both one's weaknesses and one's strengths. One should be aware of one's weaknesses in order to self-limit practice in areas in which one has limited competence, to help set appropriate learning goals, and to identify areas that "should be accepted as forever outside one's scope of competent practice" [32]. Knowing one's strengths, meanwhile, allows a physician both to "act with appropriate confidence" and to "set appropriately challenging learning goals" that push the boundaries of the physician's knowledge [32].

If self-assessment is to fulfill these functions, physicians need to reflect on past performance to evaluate not only their general abilities but also specific completed performances. At the same time, they must use self-assessment predictively to assess how likely they are to be able to manage new challenges and new situations. More important, physicians should understand self-assessment as an ongoing process of monitoring tasks during performance [3]. The ability to monitor oneself in the moment is critical to physicians' ethical responsibility to practice safely, at the top of their expertise but not beyond it.

Expert practitioners rely on pattern recognition and other automatic resources to be able to think and act intuitively. As noted above, an important component of expert judgment is transitioning effectively from automatic modes of thinking to more effortful modes as the situation requires. Self-awareness, in the form of attentive self-observation (metacognitive monitoring), alerts physicians when they need to direct additional cognitive resources to the immediate task. For example, among surgeons, knowing when to "slow down" during a procedure is critical to competent

professional performance, whether that means actually stopping the procedure, withdrawing attention from the surrounding environment to focus more intently on the task at hand, or removing distractions from the operating environment [25].

Physicians should also be sensitive to the ways that interruptions and distractions, which are common in health care settings, can affect competence in the moment [34,35], by disrupting memory processes, particularly the "prospective memory"—i.e., "a memory performance in which a person must recall an intention or plan in the future without an agent telling them to do so"—important for resuming interrupted tasks [35,36]. Systems-level interventions have been shown to help reduce the number or type of interruptions and distractions and mitigate their impact on medical errors [37].

A key aspect of competence is demonstrating situation-specific awareness in the moment of being at the boundaries of one's knowledge and responding accordingly [33]. Slowing down, looking things up, consulting a colleague, or deferring from taking on a case can all be appropriate responses when physicians' self-awareness tells them they are at the limits of their abilities. The capacity for ongoing, attentive self-observation, for "mindful" practice, is an essential marker of competence broadly understood:

Safe practice in a health professional's day-to-day performance requires an awareness of when one lacks the specific knowledge or skill to make a good decision regarding a particular patient.... This decision making in context is importantly different from being able to accurately rate one's own strengths and weaknesses in an acontextual manner.... Safe practice requires that self-assessment be conceptualized as repeatedly enacted, situationally relevant assessments of self-efficacy and ongoing 'reflection-in-practice,' addressing emergent problems and continuously monitoring one's ability to effectively solve the current problem [32].

Self-aware physicians discern when they are no longer comfortable handling a particular type of case and know when they need to obtain more information or need additional resources to supplement their own skills [32]. Self-aware physicians are also alert to how external stressors—the death of a loved one or other family crisis, or the reorganization of their practice, for example—may be affecting their ability to provide care appropriately at a given time. They recognize when they should ask themselves whether they should postpone care, arrange to have a colleague provide care, or otherwise find ways to protect the patient's well-being.

MAINTAINING COMPETENCE ACROSS A PRACTICE LIFETIME

For physicians, the ideal is not simply to be "good" practitioners, but to excel throughout their professional careers. This ideal holds not just over the course of a sustained clinical practice, but equally when physicians re-enter practice after a hiatus, transition from active patient care to roles as educators or administrators, or take on other functions in health care. Self-assessment and self-awareness are central to achieving that goal.

A variety of strategies are available to physicians to support effective self-assessment and help physicians cultivate the kind of self-awareness that enables them to "know when to slow down" in day-to-day practice. One such strategy might be to create a portfolio of materials for reflection in the form of written descriptions, audio or video recording, or photos of encounters with patients that can provide evidence of learning, achievement and accomplishment [16] or of opportunities to improve practice. A strength of portfolios as a tool for assessing one's practice is that, unlike standardized examinations, they are drawn from one's actual work and require self-reflection [15].

As noted above, to be effective, self-assessment must be joined with input from others. Well-designed multi-source feedback can be useful in this regard, particularly for providing information about interpersonal behaviors [14]. Research has shown that a four-domain tool with a simple response that elicits feedback about how well one maintains trust and professional relationships with patients, one's communication and teamwork skills, and accessibility offers a valid, reliable tool that can have practical value in helping to correct poor behavior and, just as important, consolidate good behavior [14]. Informal arrangements among colleagues to provide thoughtful feedback will not have the rigor of a validated tool but can accomplish similar ends.

Reflective practice, that is, the habit of using critical reflection to learn from experience, is essential to developing and maintaining competence across a physician's practice lifetime [38]. It enables physicians to "integrate personal beliefs, attitudes, and values in the context of professional culture," and to bridge new and existing knowledge. Studies suggest

that reflective thinking can be assessed, and that it can be developed, but also that the habit can be lost over time with increasing years in practice [38].

"Mindful practice," that is, being fully present in everyday experience and aware of one's own mental processes (including those that cloud decision making) [39], sustains the attitudes and skills that are central to self-awareness. Medical training, with its fatigue, dogmatism, and emphasis on behavior over consciousness, erects barriers to mindful practice, while an individual's unexamined negative emotions, failure of imagination, and literal-mindedness can do likewise. Mindfulness can be self-taught, but for most it is most effectively learned in relationship with a mentor or guide. Nonetheless, despite challenges, there are myriad ways physicians can cultivate mindfulness. Meditation, which may come first to mind, is one, but so is keeping a journal, reviewing videos of encounters with patients, or seeking insight from critical incident reports [39].

"Exemplary physicians," one scholar notes, "seem to have a capacity for self-critical reflection that pervades all aspects of practice, including being present with the patient, solving problems, eliciting and transmitting information, making evidence-based decisions, performing technical skills, and defining their own values" [39].

RECOMMENDATION

The Council on Ethical and Judicial Affairs recommends that the following be adopted and the remainder of this report be filed:

The expectation that physicians will provide competent care is central to medicine. It undergirds professional autonomy and the privilege of self-regulation granted by society. To this end, medical schools, residency and fellowship programs, specialty boards, and other health care organizations regularly assess physicians' technical knowledge and skills.

However, as an ethical responsibility competence encompasses more than medical knowledge and skill. It requires physicians to understand that as a practical matter in the care of actual patients, competence is fluid and dependent on context. Each phase of a medical career, from medical school through retirement, carries its own implications for what a physician should know and be able to do to practice safely and to maintain effective relationships with patients and with colleagues. Physicians at all stages of their professional lives need to be able to recognize when they are and when they are not able to provide appropriate care for the patient in front of them or the patients in their practice as a whole.

To fulfill the ethical responsibility of competence, individual physicians and physicians in training should strive to:

- (a) Cultivate continuous self-awareness and self-observation.
- (b) Recognize that different points of transition in professional life can make different demands on competence.
- (c) Take advantage of well-designed tools for self-assessment appropriate to their practice settings and patient populations.
- (d) Seek feedback from peers and others.
- (e) Be attentive to environmental and other factors that may compromise their ability to bring appropriate skills to the care of individual patients and act in the patient's best interest.
- (f) Intervene in a timely and appropriate manner when a colleague's ability to practice safely is compromised by impairment, in keeping with ethics guidance.

Medicine as a profession should continue to refine mechanisms for assessing knowledge and skill and should develop meaningful opportunities for physicians and physicians in training to hone their ability to be self-reflective and attentive in the moment.

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2. STUDY AID-IN-DYING AS END-OF-LIFE OPTION (RESOLUTION 15-A-16) THE NEED TO DISTINGUISH "PHYSICIAN-ASSISTED SUICIDE" AND "AID IN DYING" (RESOLUTION 14-A-17)

Reference committee hearing: see report of Reference Committee on Amendments to Constitution and Bylaws.

HOUSE ACTION: REFERRED

At the 2016 Annual Meeting, the House of Delegates referred Resolution 15-A-16, "Study Aid-in-Dying as End-of-Life Option," presented by the Oregon Delegation, which asked:

That our American Medical Association (AMA) and its Council on Judicial and Ethical Affairs (CEJA), study the issue of medical aid-in-dying with consideration of (1) data collected from the states that currently authorize aid-in-dying, and (2) input from some of the physicians who have provided medical aid-in-dying to qualified patients, and report back to the HOD at the 2017 Annual Meeting with recommendation regarding the AMA taking a neutral stance on physician "aid-in-dying."

At the following Annual Meeting in June 2017, the House of Delegates similarly referred Resolution 14-A-17, "The Need to Distinguish between 'Physician-Assisted Suicide' and 'Aid in Dying'" (presented by M. Zuhdi Jasser, MD), which asked that our AMA:

(1) as a matter of organizational policy, when referring to what it currently defines as 'Physician Assisted Suicide' avoid any replacement with the phrase 'Aid in Dying' when describing what has long been understood by the AMA to specifically be 'Physician Assisted Suicide'; (2) develop definitions and a clear distinction between what is meant when the AMA uses the phrase 'Physician Assisted Suicide' and the phrase 'Aid in Dying'; and (3) fully utilize these definitions and distinctions in organizational policy, discussions, and position statements regarding both 'Physician Assisted Suicide' and 'Aid in Dying.'

This report by the Council on Ethical and Judicial Affairs addresses the concerns expressed in Resolutions 15-A-16 and 14-A-17. In carrying out its review of issues in this area, CEJA reviewed the philosophical and empirical literature, sought input from the House of Delegates through an I-16 educational program on physician-assisted suicide, an informal "open house" at A-17, and its I-17 Open Forum. The council wishes to express its sincere appreciation for participants' contributions during these sessions and for additional written communications received from multiple stakeholders, which have enhanced its deliberations.

The council observes that the ethical arguments advanced today supporting and opposing "physician-assisted suicide" or "aid in dying" are fundamentally unchanged from those examined in CEJA's 1991 report on this topic [1]. The present report does not rehearse these arguments again as such. Rather, it considers the implications of the legalization of assisted suicide in the United States since the adoption of Opinion E-5.7, "Physician-Assisted Suicide," in 1994.

"ASSISTED SUICIDE," "AID IN DYING," OR "DEATH WITH DIGNITY"?

Not surprisingly, the terms stakeholders use to refer the practice of physicians prescribing lethal medication to be self-administered by patients in many ways reflect the different ethical perspectives that inform ongoing societal debate. Proponents of physician participation often use language that casts the practice in a positive light. "Death with dignity" foregrounds patients' values and goals, while "aid in dying" invokes physicians' commitment to succor and support. Such connotations are visible in the titles of relevant legislation in states that have legalized the practice: "Death with Dignity" (Oregon, Washington, District of Columbia), "Patient Choice and Control at the End of Life" (Vermont), "End of Life Options" (California, Colorado), "Our Care Our Choice Act" (Hawaii), and in Canada's "Medical Aid in Dying."

Correspondingly, those who oppose physician provision of lethal medications refer to the practice as "physician-assisted suicide," with its negative connotations regarding patients' psychological state and its suggestion that physicians are complicit in something that, in other contexts, they would seek to prevent. The language of dignity and aid, critics contend, are euphemisms [2]; their use obscures or sanitizes the activity. In their view such language characterizes physicians' role in a way that risks construing an act that is ethically unacceptable as good medical practice [3]. Still others, meanwhile, argue that the choice by terminally ill patients to take action to end their own lives with the assistance of their physician is distinct from what is traditionally understood as "suicide" [4].

The council recognizes that choosing one term of art over others can carry multiple, and not always intended messages. However, in the absence of a perfect option, CEJA believes ethical deliberation and debate is best served by using plainly descriptive language. In the council's view, despite its negative connotations [5], the term "physician assisted suicide" describes the practice with the greatest precision. Most importantly, it clearly distinguishes the practice from euthanasia [1]. The terms "aid in dying" or "death with dignity" could be used to describe either euthanasia or palliative/hospice care at the end of life and this degree of ambiguity is unacceptable for providing ethical guidance.

COMMON GROUND

Beneath the seemingly incommensurate perspectives that feature prominently in public and professional debate about writing a prescription to provide patients with the means to end life if they so choose, CEJA perceives a deeply and broadly shared vision of what matters at the end of life. A vision that is characterized by hope for a death that preserves dignity, a sense of the sacredness of ministering to a patient at the end of life, recognition of the relief of suffering as the deepest aim of medicine, and fully voluntary participation on the part of both patient and physician in decisions about how to approach the end of life.

Differences lie in the forms these deep commitments take in concrete decisions and actions. CEJA believes that thoughtful, morally admirable individuals hold diverging, yet equally deeply held, and well-considered perspectives about physician-assisted suicide that govern how these shared commitments are ultimately expressed. For one patient, dying "with dignity" may mean accepting the end of life however it comes as gracefully as one can; for another, it may mean being able to exercise some measure of control over the circumstances in which death occurs. For some physicians, the sacredness of ministering to a terminally ill or dying patient and the duty not to abandon the patient preclude the possibility of supporting patients in hastening their death. For others, not to provide a prescription for lethal medication in response to a patient's sincere request violates that same commitment and duty. Both groups of physicians base their view of ethical practice on the guidance of Principle I of the AMA *Principles of Medical Ethics*: "A physician shall be dedicated to providing competent medical care, with compassion and respect for human dignity and rights."

So too, how physicians understand and act on the goals of relieving suffering, respecting autonomy, and maintaining dignity at the end of life is directed by identity-conferring beliefs and values that may not be commensurate. Where one physician understands providing the means to hasten death to be an abrogation of the physician's fundamental role as healer that forecloses any possibility of offering care that respects dignity, another in equally good faith understands supporting a patient's request for aid in hastening a foreseen death to be an expression of care and compassion.

IRREDUCIBLE DIFFERENCES IN MORAL PERSPECTIVES ON PHYSICIAN-ASSISTED SUICIDE

How to respond when coherent, consistent, and deeply held beliefs yield irreducibly different judgments about what is an ethically permissible course of action is profoundly challenging. With respect to physician-assisted suicide, some professional organizations—for example, the American Academy of Hospice and Palliative Medicine [6]—have adopted a position of "studied neutrality." Positions of studied neutrality neither endorse nor oppose the contested practice, but instead are intended to respect that there are irreducible differences among the deeply held beliefs and values that inform public and professional perspectives [6,7], and to leave space open for ongoing discussion. Nonetheless, as a policy position, studied neutrality has been criticized as neither neutral or appropriate for organized medicine [8], and as being open to unintended consequences, including stifling the very debate it purports to encourage or being read as little more than acquiescence with the contested practice [9].

CEJA approaches the condition of irreducible difference from a different direction. In its 2014 report on exercise of conscience, the Council noted that "health care professionals may hold very different core beliefs and thus reach very different decisions based on those core beliefs, yet equally act according to the dictates of conscience. For example, a physician who chooses to provide abortions on the basis of a deeply held belief in protecting women's autonomy makes the same kind of moral claim to conscience as does a physician who refuses to provide abortion on the basis of respect for the sanctity of life of the fetus" [10].

Importantly, decisions taken in conscience are not simply idiosyncratic; they do not rest on intuition or emotion. Rather, such decisions are based on "substantive, coherent, and reasonably stable" values and principles [10]. Physicians must be able to articulate how those values and principles justify the action in question.

The ethical arguments offered for more than two decades by those who support and those who oppose physician participation in assisted suicide reflect the diverging "substantive, coherent, and reasonably stable" values and principles within the profession and the wider moral community. While supporters and opponents of physician-assisted suicide share a common commitment to "compassion and respect for human dignity and rights" (AMA Principles of Medical Ethics, I), they draw different moral conclusions from the underlying principle they share. As psychiatrist Harvey Chochinov observed with respect to the stakeholders interviewed by Canadian Supreme Court's advisory panel on physician-assisted death, "neither those who are strongly supportive nor those who are opposed hold a monopoly on integrity and a genuine concern for the well-being of people contemplating end of life. Equally true: neither side is immune from impulses shaped more by ideology than a deep and nuanced understanding of how to best honor and address the needs of people who are suffering" [11].

THE RISK OF UNINTENDED CONSEQUENCES

From the earliest days of the debate, a prominent argument raised against permitting physician-assisted suicide has been that doing so will have adverse consequences for individual patients, the medical profession, and society at large. Scholars have cited the prospect that boundaries will be eroded and practice will be extended beyond competent, terminally ill adult patients; to patients with psychiatric disorders, children; or that criteria will be broadened beyond physical suffering to encompass existential suffering; or that stigmatized or socioeconomically disadvantaged patients will be coerced or encouraged to end their lives. Concerns have also been expressed that permitting the practice will compromise the integrity of the profession, undermine trust, and harm the physicians and other health care professionals who participate; and that forces outside medicine will unduly influence decisions.

The question whether safeguards—which in the U.S. jurisdictions that permit assisted suicide, restrict the practice to terminally ill adult patients who have decision-making capacity and who voluntarily request assisted suicide, along with procedural and reporting requirements—can actually protect patients and sustain the integrity of medicine remains deeply contested. Some studies have "found no evidence to justify the grave and important concern often expressed about the potential for abuse—namely, the fear that legalized physician-assisted dying will target the vulnerable or pose the greatest risk to people in vulnerable groups" [12], others question whether the available data can in fact support any such conclusions, finding the evidence cited variously flawed [13], inadequate [14], or distorted [15].

Although cross-cultural comparisons are problematic [16], current evidence from Europe does tell a cautionary tale. Recent findings from studies in Belgium and the Netherlands, both countries that permit euthanasia as well as physician-assisted suicide, mitigate some fears but underscore others [17]. For example, research in the Netherlands

has found that "requests characterized by psychological as opposed to physical suffering were more likely to be rejected, as were requests by individuals who lived alone," mitigating fears that "solitary, depressed individuals with potentially reversible conditions might successfully end their lives." At the same time, however, among patients who obtained euthanasia or assisted suicide, nearly 4 percent "reported only psychological suffering." At the level of anecdote, a description of a case of euthanasia in Belgium elicited widespread concern about the emergence of a "slippery slope" [18].

Studies have also raised questions about how effective retrospective review of decisions to provide euthanasia/assisted suicide is in policing practice [19,20]. A qualitative analysis of cases that Dutch regional euthanasia committees determined had not met legal "due care criteria" found that such reviews focus on procedural considerations and do not "directly assess the actual eligibility" of the patients who obtained euthanasia [19]. A separate study of cases in which psychiatric patients obtained euthanasia found that physicians' reports "stated that psychosis or depression did or did not affect capacity but provided little explanation regarding their judgments" and that review committees "generally accepted the judgment of the physician performing EAS [euthanasia or physician-assisted suicide]" [20]. It remains an open question whether reviews that are not able to assess physicians' reasoning truly offer the protection they are intended to provide. To the extent that reporting and data collection in states that permit physician-assisted suicide have similar limitations, oversight of practice may not be adequate.

Medicine must learn from this experience. Where physician-assisted suicide is legalized, safeguards can and should be improved—e.g., "[t]o increase safeguards, states could consider introducing multidisciplinary panels to support patients through the entire process, including verifying consent and capacity, ensuring appropriate psychosocial counseling, and discussing all palliative and end-of-life options" [21]. Both the state and the medical profession have a responsibility to monitor ongoing practice in a meaningful way and to address promptly compromises in safeguards should any be discovered. It is equally important that strong practices be identified and encouraged across all jurisdictions that permit physicians to assist suicide. Health care organizations in California and Canada, for example, have shared richly descriptive reports of practices adopted in response to the recent legalization of "aid in dying" in those jurisdictions that seek to address concerns about quality of practice and data collection [22,23].

Medicine must also acknowledge, however, that evidence (no matter how robust) that there have not yet been adverse consequences cannot guarantee that such consequences would not occur in the future. As a recent commentary noted, "[p]art of the problem with the slippery slope is you never know when you are on it" [17].

SAFEGUARDING DECISIONS AT THE END OF LIFE

CEJA has found that just as there are shared commitments behind deep differences regarding physician-assisted suicide, there are also shared concerns about how to understand the available evidence. For example, in the council's recent Open Forum, both proponents and opponents of physician-assisted suicide observed that in the U.S., debate occurs against the backdrop of a health care system in which patients have uneven access to care, including access to high quality end-of-life care. They also noted that patients and physicians too often still do not have the conversations they should about death and dying, and that too few patients are aware of the range of options for end-of-life care, raising concern that many patients may be led to request assisted suicide because they don't understand the degree of relief of suffering state-of-the-art palliative care can offer. Participants who in other respects held very different views concurred as well that patients may be vulnerable to coercion, particularly patients who are in other ways disadvantaged; and expressed concern in common that forces external to medicine could adversely influence practice.

These are much the same concerns the Institute of Medicine identified in its 2015 report, *Dying in America* [24]. They are concerns echoed in a February 2018 workshop on physician-assisted death convened by the National Academies of Science, Engineering and Medicine [25]. They underscore how important it is to understand *why* a patient requests assisted suicide as a starting point for care [26].

Patient requests for assisted suicide invite physicians to have the kind of difficult conversations that are too often avoided. They open opportunities to explore the patient's goals and concerns, to learn what about the situation the individual finds intolerable and to respond creatively to the patient's needs other than providing the means to end life—by such means as better managing symptoms, arranging for psychosocial or spiritual support, treating depression, and helping the patient to understand more clearly how the future is likely to unfold [5,27]. Medicine as a profession must ensure that physicians are skillful in engaging in these difficult conversations and knowledgeable about the options available to terminally ill patients [28]. The profession also has a responsibility to advocate for

adequate resources for end-of-life care [16,28], particularly for patients from disadvantaged groups. The availability of assisted suicide where it is legal must not be allowed to interfere with excellent care at the end of life.

CONCLUSION

At the core of public and professional debate, the council believes, is the aspiration that every patient come to the end of life as free as possible from suffering that does not serve the patient's deepest self-defining beliefs and in the presence of trusted companions, including where feasible and when the patient desires, the presence of a trusted physician. As Timothy Quill noted more than 20 years ago, "dying patients do not have the luxury of choosing not to undertake the journey, or of separating their person from their disease" [27]. Decisions about how to approach the end of life are among the most intimate that patients, families, and their physicians make. Respecting the intimacy and the authenticity of those relationships is essential if our common ideal is to be achieved.

While supporters and opponents of physician-assisted suicide share a common commitment to "compassion and respect for human dignity and rights" (<u>AMA Principles of Medical Ethics</u>, I), they draw different moral conclusions from the underlying principle they share. Where one physician understands providing the means to hasten death to be an abrogation of the physician's fundamental role as healer that forecloses any possibility of offering care that respects dignity, another in equally good faith understands supporting a patient's request for aid in hastening a foreseen death to be an expression of care and compassion.

RECOMMENDATION

The Council on Ethical and Judicial Affairs has reviewed the literature and received thoughtful input from numerous individuals and organizations to inform its deliberations, and is deeply grateful to all who shared their insights. CEJA engaged in extensive, often passionate discussion about how to interpret the *Code of Medical Ethics* in light of ongoing debate and the irreducible differences in moral perspectives identified above. The council recognized that supporters and opponents share a fundamental commitment to values of care, compassion, respect, and dignity, but diverge in drawing different moral conclusions from those underlying values in equally good faith. The council further recognized that medicine must learn from experience of physician-assisted suicide, and must ensure that, where the practice is legal, safeguards are improved.

After careful consideration, CEJA concludes that in existing opinions on physician-assisted suicide and the exercise of conscience, the *Code* offers guidance to support physicians and the patients they serve in making well-considered, mutually respectful decisions about legally available options for care at the end of life in the intimacy of a patient-physician relationship.

The Council on Ethical and Judicial Affairs therefore recommends that the *Code of Medical Ethics* not be amended, that Resolutions 15-A-16 and 14-A-17 not be adopted and that the remainder of the report be filed.

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3. PEDIATRIC DECISION MAKING (RESOLUTIONS 3-A-16 AND 13-A-18)

Reference committee hearing: see report of Reference Committee on Amendments to Constitution and Bylaws.

HOUSE ACTION: RECOMMENDATION ADOPTED

IN LIEU OF RESOLUTIONS 3-A-16 AND 13-A-18

REMAINDER OF REPORT FILED

See Opinion E-2.2.1

At the 2016 Interim Meeting, the American Medical Association (AMA) House of Delegates referred Board of Trustees Report 7-I-16, "Supporting Autonomy for Patients with Differences of Sex Development (DSD)," responding to Resolution 3-A-16 of the same title introduced by the Medical Student Section, which asked:

That our AMA affirm that medically unnecessary surgeries in individuals born with differences of sex development are unethical and should be avoided until the patient can actively participate in decision-making.

Testimony regarding BOT 7-I-16 expressed concern about lack of expert insight into the medical complexities in treating differences of sex development in pediatric patients in its analysis and possible unintended consequences of its recommendations.

Resolution 13-A-18, "Opposing Surgical Sex Assignment of Infants with Differences of Sex Development," brought by the Michigan Delegation, asked

That our American Medical Association oppose the assignment of gender binary sex to infants with differences in sex development through surgical intervention outside of the necessity of physical functioning for an infant and believes children should have meaningful input into any gender assignment surgery.

Noting that the issue was under study by the Council on Ethical and Judicial Affairs (CEJA), the House of Delegates referred this resolution so that the council could address it during its ongoing deliberations in this area.

This CEJA report provides ethics guidance for physicians in relation to the concerns expressed in Resolutions 3-A-16 and 13-A-18. The council is grateful for participants' contributions during reference committee hearings and for additional written communications received from multiple stakeholders, which have greatly enhanced its deliberations.

CLARIFYING THE QUESTION

Resolutions 3-A-16 and 13-A-18 speak to clinical decisions that have enormous significance for individual patients and families, decisions that also implicate socially and culturally sensitive issues of embodiment, gender, and sexuality. Each asks AMA to endorse specific broadly framed statements intentionally limiting the range of decisions physicians, patients, and families should reach. Yet as multiple stakeholders have pointed out, the label "differences [or disorders] of sex development" is problematic in that it encompasses a very broad range of conditions that carry quite variable implications for patients' immediate and longer-term health, making for an extremely complex clinical picture overall [e.g., 1,2,3].

It is, moreover, a clinical picture in which the body of evidence available to inform decisions remains both limited and contested in important ways. In part, this reflects the difficulty in collecting data, given the relative rarity of these conditions and the sheer range of conditions currently labeled "differences of sex development" [e.g., 4]. Importantly, it reflects divergence among understandings of children's physical and psychosocial development on which stakeholders' perspectives rest [e.g., 4,5,6,7,8,9].

Literature reviews that stakeholders have provided to help inform CEJA's deliberations indicate ongoing, significant differences in how the published evidence is interpreted [e.g., 1,10]. Concerns have been expressed about not just the quantity, but also the quality of the data available to inform clinical decisions, with questions raised about whether studies have asked the "right" question and about how well the framing of key research questions and the methodology, sample size, and data analysis support the conclusions drawn in a given study [e.g., 11]. Stakeholders concur on the need for systematic, well-designed research to provide robust evidence on the long-term outcomes that are meaningful to patients of different clinical approaches.

CEJA appreciates the challenge this state of affairs poses for families and physicians who strive to make clinically well-informed decisions for individual children. Thoughtful stakeholders differ in good faith, at times profoundly, about whether and at what developmental stage in the child's life intervention should be considered medically essential, preferred, or acceptable for children born with differences of sex development. Despite these differences, stakeholders clearly share a deep professional commitment to serving the best interest of pediatric patients.

However, to the extent that Resolutions 3-A-16 and 13-A-18 call on the council to address the lack of clinical consensus, they seek guidance that is not within CEJA's purview to offer. It is not the council's role to adjudicate clinical disagreement or to prescribe what manner of decision is "correct" or "best," but rather to clarify the values at issue and identify what factors must be considered to arrive at an *ethically sound* decision in any given patient's unique situation.

MAKING DECISIONS FOR PEDIATRIC PATIENTS

Health care decisions for pediatric patients necessarily have a different character than decisions for adult patients. Decisions for children are made in the context of a three-way relationship among patient, parents (or guardians), and physician rather than the patient-physician dyad typical of decision making for most adult patients. Further, except for emancipated minors, who are authorized to make their own health care decisions, or certain decisions that other minor patients are permitted to make independently (e.g., <u>E-2.3.3</u>, Confidential Care for Minors), decisions for pediatric patients are made, not by the patient, but by parents/guardians acting on the patient's behalf. Finally, the substituted judgment standard for surrogate decision making on behalf of adult patients is for the most part unavailable to those

who make decisions for minors, insofar as children, especially very young children, are unlikely to have formed settled views and preferences upon which substituted judgment could be based.

The Patient's "Best Interests"

Ethically, and legally, then, parents are expected to make health care decisions in their children's best interests. As the persons best positioned to understand their child's unique needs and interests, parents/guardians are asked to fulfill the dual responsibility of both protecting their children and, at the same time, empowering them and promoting development of the child's capacity to become an independent decision maker. Parents/guardians are expected to safeguard their children's physical health and well-being *and* to nurture their children's developing personhood and autonomy.

Best interests, and thus goals for care, then, should be understood broadly, as encompassing more than simply medical considerations. Parents/guardians are indeed expected to weigh the clinical benefits and risks of treatment alternatives, including the option of no treatment or the timing of interventions, but to do so against the broader background of likely impact on the child's psychosocial well-being, relationships within the family, and family resources and values. As CEJA noted in its original report on decisions for pediatric patients (2007), because families provide a child's usual, often only, source of support and care, the family's needs and interests can also be relevant to treatment decisions. The council further observed that, "If none of the reasonable alternatives the health care team recommends can be reconciled with the family's circumstances, deciding on the best course of treatment may be 'an exercise in psychosocial, as well as technical medical, expertise" [12].

The Committee on Bioethics of the American Academy of Pediatrics similarly holds that best interest should be understood broadly, to encompass more than purely clinical considerations. The committee urges decision makers to "acknowledge the pediatric patient's emotional, social, and medical concerns along with the interests of the child's family in the process of medical decision making" [13]. However, the committee argues, the concept of "harm" may be a "more realistic standard" for decisions on behalf of pediatric patients, noting that,

The intent of the harm principle is not to identify a single course of action that is in the minor's interest or is the physician's preferred approach, but to identify a harm threshold below which parental decisions will not be tolerated ... [13].

Using the harm principle to inform choices for individual patients, including pediatric patients, requires that decision makers take into account the kind, degree and duration of foreseeable harms, as well as the likelihood of their occurrence.

Engaging Children in Care Decisions

Absent reason to believe otherwise, parents/guardians are understood to be best able to take a child's long-term interests to heart in reaching a decision about care and in general their decisions should be respected. But that does not mean children should have no role in the decision-making process. In its original report CEJA noted that "the ethical principle of respect for persons also applies to children" and urged physicians to seek pediatric patients' assent to decisions made on their behalf [12,13]. Assent, the council observed, "weighs a child's ability to understand options and potential outcomes and to communicate preferences" [12].

CEJA recognized that "the notion of assent can be applied most readily to adolescent patients," but instructed physicians to evaluate younger patients' "cognitive capacities and judgment to determine if they can understand the risks and benefits of treatment" and to engage them accordingly in the decision-making process. Not all information is cognitively and emotionally appropriate for every pediatric patient, nor is it necessary to communicate all information about a diagnosis and proposed care all at once. As for any patient, physicians should assess the amount of information the individual is capable of receiving at a given time and tailor disclosure to meet patients' needs, preferences, and ability to understand (E-2.1.3, Withholding Information from Patients).

Respecting children as (developing) persons also entails seeking to understand their reasons for disagreeing with treatment decisions. When an intervention is not immediately necessary to safeguard the child's welfare, CEJA has argued, physicians (and parents/guardians) should respect a child's refusal to assent to proposed treatment. Even when immediate treatment is essential to preserve well-being, physicians should explore the child's reason for dissent, when

circumstances permit. The more mature a minor patient is, the better able to understand what a decision will mean, and the more clearly the child can communicate preferences, the stronger the ethical obligation to engage young patients in decisions about their own care. As CEJA noted in refining its guidance on decisions for pediatric patients in 2010, communicating even sensitive and potentially frightening information—about HIV status or a terminal diagnosis, for example—can improve a child's well-being [14].

Preserving Future Choices

In fulfilling their responsibility to nurture their children's developing capacity to make autonomous decisions, parents/guardians are expected to make health care decisions that will least impinge on children's opportunity to make important life choices themselves in the future. In general, decisions taken now on a child's behalf should be made with an eye not to foreclose decisions the child can reasonably be expected, in time, to want and be able to make independently, realizing that choosing *not* to have a treatment or procedure performed also forecloses a future choice. This "right to an open future" is not absolute, of course. Parents/guardians must balance their responsibility to preserve the child's opportunity for future exercise of self-determination with the need to protect the child's immediate well-being. Physicians should be prepared to support them in that process, providing the best available data to inform their decision and directing them to appropriate psychosocial and other resources.

Finally, the opportunity to meet with and learn from others who have faced similar decisions can provide valuable firsthand insight and support that clinicians themselves may not be able to offer. Physicians should familiarize themselves with local peer support groups as resources to help inform decision making by parents and their minor children.

A CONTINUUM OF DECISIONS

The degree of difficulty faced by parents/guardians in making well-considered, ethically justifiable decisions for young patients who are not able to make their own health care choices varies across a continuum. At one end of that continuum are decisions that involve interventions about which there is consensus in the professional community, whose benefits are significant, supported by robust evidence, and significantly outweigh the risks they pose (the likelihood and magnitude of which are themselves well understood). In those situations, physicians have a responsibility to persuade reluctant parents/guardians to accept the intervention on their child's behalf. Where the intervention would preserve life or avert serious harm and disagreement persists despite efforts to resolve the tension, physicians have legal and ethical obligations to seek court interventions against parental refusal of treatment.

At the other end are decisions that involve interventions that carry significant risk of harm or that currently available evidence would suggest offer little prospect of clinical benefit or cannot reasonably be expected to achieve the intended goal. In these cases, physicians have a responsibility to dissuade parents/guardians from pursuing the intervention, especially when it is irreversible, and should decline to provide the requested care when a patient's parents/guardian persist, in keeping with ethics guidance (e.g., <u>E-5.5</u>, Medically Ineffective Interventions).

Between are decisions that involve interventions about which physicians may in good faith reach diverging professional judgments, and for which evidence as to short- and long-term benefit and risk is limited, equivocal, or contested. In such situations, how physicians interpret available evidence and its implications for an individual patient is shaped in significant part by their understanding of how to balance the competing values of beneficence and respect in upholding medicine's foundational commitment to serve the patient's (best) interests. In this "grey zone" physicians are challenged to negotiate with decision makers a shared agreement about how to understand this patient's medical and psychosocial interests and what plan of care will best serve those interests in the individual's unique circumstances and in most cases should give great deference to parental preferences.

SHOULD DECISIONS ABOUT DSD BE DIFFERENT FROM OTHER DECISIONS?

Helping parents/guardians make decisions for young patients with differences of sex development is inescapably challenging given the range of conditions at issue and the physiological/clinical complexity of many of those conditions. The fact that DSDs are entangled with socially and culturally sensitive issues of bodies, genders, and sex compounds that challenge—the more so in an environment in which a binary understanding of sex and gender is increasingly contested.

Yet whether these decisions are more challenging than decisions for pediatric patients with other diagnoses—say, decisions about cochlear implants for congenitally deaf newborns—is far from clear. The specific interventions about which decisions must be made and the timing of those decisions will be sensitive to the child's clinical situation, of course, but the fundamental task facing parents/guardians and physicians will still be to agree on a path forward that balances safeguarding the child's well-being, short and longer term, and nurturing the child's development as an individual with capacity to make decisions autonomously.

Regardless of the specific decision at issue, it is important that parents/guardians and physicians appreciate the fact that a pediatric patient will of necessity live out the consequences of a choice made by others—one with which the individual may ultimately come to disagree. Moreover, when decisions implicate issues that are socially and culturally divisive, such as sex assignment and "normalizing" surgery for DSD patients, patients and their families can be thrust into the role of agent of social change or preserver of the status quo, knowingly, willingly, or otherwise [4]. Ensuring that parents/guardians have the information and—absent immediate, life-threatening emergency—the time to make well-considered decisions is essential.

For physicians, supporting thoughtful, ethically sound decision making for all pediatric patients, especially very young patients, requires that they consider several fundamental questions and tailor recommendations to the individual's specific circumstances:

- What is this child's likely developmental course without (immediate) intervention? How strong is the evidence to support this prognosis?
- What are these parents/guardians' (and this patient's) overall goals for care?
- To what extent is the clinical anomaly a significant threat to health, immediately and in the long term?
- Is providing the proposed intervention at this stage in the child's development supported by clear, high quality evidence?
- Could other interventions reasonably be staged developmentally to allow the patient and family time to gain experience living with the condition and to reflect on and perhaps adjust goals for care?
- To what extent would the proposed intervention (or lack of intervention) foreclose important life choices for the adolescent and adult the child will become? Are there reasonable alternatives that would address immediate clinical needs while preserving opportunity to make important future choices?
- What resources will the child and family need to support the child's healthy physical and psychosocial development? How can the physician assist in making those resources available to the patient and family?

COMING TO COMMON GROUND

Parents/guardians are expected to make health care decisions in children's "best interest." In doing so, they are expected both to protect children and, at the same time, to empower children and promote children's developing capacity to become independent decision makers. To nurture this developing capacity, health care decisions are preferable that will least impinge on children's opportunity to make important life choices themselves in the future.

Making decisions for children that involve socially or culturally sensitive issues—for example, whether or how to discuss a terminal diagnosis with a child, or whether, when, or how to intervene medically for conditions that involve differences of sex development—is always challenging. The greater the uncertainty or lack of robust evidence supporting alternative courses of action, the more difficult the task becomes.

In such circumstances, despite a common commitment to serving the best interest of pediatric patients, thoughtful stakeholders may, in good faith, differ about whether a particular intervention, at a particular time is medically essential, preferred, or acceptable. When no single approach can be said a priori to be "best." Ethically sound practice requires that decisions be carefully tailored for each patient in a process of shared decision making among parents/guardians, physician and the patient (in keeping with the child's capacity to participate). Decision makers should seek a shared understanding of goals for care in creating a treatment plan that respects the unique needs, values, and preferences of the individual patient and family.

RECOMMENDATION

In light of the foregoing analysis, the Council on Ethical and Judicial Affairs recommends that Opinion E-2.2.1, "Pediatric Decision Making," be amended by substitution as follows in lieu of Resolutions 3-A-16, "Supporting

Autonomy for Patients with Differences of Sex Development (DSD),"and 13-A-18, "Opposing Surgical Sex Assignment of Infants with Differences of Sex Development," and the remainder of this report be filed:

As the persons best positioned to understand their child's unique needs and interests, parents (or guardians) are asked to fill the dual responsibility of protecting their children and, at the same time, empowering them and promoting development of children's capacity to become independent decision makers. In giving or withholding permission for medical treatment for their children, parents/guardians are expected to safeguard their children's physical health and well-being and to nurture their children's developing personhood and autonomy.

But parents' authority as decision makers does not mean children should have no role in the decision-making process. Respect and shared decision making remain important in the context of decisions for minors. Thus, physicians should evaluate minor patients to determine if they can understand the risks and benefits of proposed treatment and tailor disclosure accordingly. The more mature a minor patient is, the better able to understand what a decision will mean, and the more clearly the child can communicate preferences, the stronger the ethical obligation to seek minor patients' assent to treatment. Except when immediate intervention is essential to preserve life or avert serious, irreversible harm, physicians and parents/guardians should respect a child's refusal to assent, and when circumstances permit should explore the child's reason for dissent.

For health care decisions involving minor patients, physicians should:

- (a) Provide compassionate, humane care to all pediatric patients.
- (b) Negotiate with parents/guardians a shared understanding of the patient's medical and psychosocial needs and interests in the context of family relationships and resources.
- (c) Develop an individualized plan of care that will best serve the patient, basing treatment recommendations on the best available evidence and in general preferring alternatives that will not foreclose important future choices by the adolescent and adult the patient will become. Where there are questions about the efficacy or long-term impact of treatment alternatives, physicians should encourage ongoing collection of data to help clarify value to patients of different approaches to care.
- (d) Work with parents/guardians to simplify complex treatment regimens whenever possible and educate parents/guardians in ways to avoid behaviors that will put the child or others at risk.
- (e) Provide a supportive environment and encourage parents/guardians to discuss the child's health status with the patient, offering to facilitate the parent-child conversation for reluctant parents. Physicians should offer education and support to minimize the psychosocial impact of socially or culturally sensitive care, including putting the patient and parents/guardians in contact with others who have dealt with similar decisions and have volunteered their support as peers.
- (f) When decisions involve life-sustaining treatment for a terminally ill child, ensure that patients have an opportunity to be involved in decision making in keeping with their ability to understand decisions and their desire to participate. Physicians should ensure that the patient and parents/guardians understand the prognosis (with and without treatment). They should discuss the option of initiating therapy with the intention of evaluating its clinical effectiveness for the patient after a specified time to determine whether it has led to improvement and confirm that if the intervention has not achieved agreed-on goals it may be discontinued.
- (g) When it is not clear whether a specific intervention promotes the patient's interests, respect the decision of the patient (if the patient has capacity and is able to express a preference) and parents/guardians.
- (h) When there is ongoing disagreement about patient's best interest or treatment recommendations, seek consultation with an ethics committee or other institutional resource.

EDITOR'S NOTE: An appendix to this report is available by contacting the Council on Ethical and Judicial Affairs.

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4. CEJA ROLE IN IMPLEMENTING H-140.837, "ANTI-HARASSMENT POLICY"

Reference committee hearing: see report of Reference Committee on Amendments to Constitution and Bylaws.

HOUSE ACTION: NOT ADOPTED

At the 2018 Annual Meeting the American Medical Association (AMA) House of Delegates (HOD) adopted with amendment the recommendations of Board of Trustees Report 20-A-18, "Anti-Harassment Policy." The HOD amended the Board's recommendations for a process to address allegations of harassment during meetings associated with the AMA to give the Council on Ethical and Judicial Affairs (CEJA) the authority and responsibility for taking disciplinary action (Policy H-140.837).

CEJA has discussed at length the recommendations of BOT Report 20-A-18 and believes that promoting safe engagement among physicians, students, staff, and other attendees during professional meetings affiliated with the AMA is an urgent organizational responsibility. However, while respecting the deliberations of the HOD, CEJA has

concluded that the council is not in a position to carry out this new responsibility as defined in the recommendations as adopted.

CEJA concluded that the responsibility to adjudicate allegations of harassment is qualitatively different from its normal judicial function. In assessing individual physicians' fitness for membership in the AMA, CEJA does not have direct, primary responsibility for taking punitive action. Rather, CEJA's decisions rest on review of extensive case files compiled by state medical boards that have already taken disciplinary action and, with rare exceptions, an interview with the physician.

With respect to allegations of harassment, CEJA is deeply concerned that this new role will be much more analogous to that of a state medical board; it also foresees the need to engage with *both* parties before reaching a final determination. CEJA strongly believes that the task demands a different set of skills than its usual adjudications, and that therefore council members would need appropriate training (provided annually as new members join the council). CEJA is also uncertain that the range of <u>disciplinary options</u> available to it in its judicial function are appropriate with respect to allegations of harassment.

CEJA is further concerned that the council as a whole has neither the resources nor flexibility required to carry out this additional responsibility effectively. The council has a substantial ongoing workload in its normal judicial function, requiring at least one full day at each of its four in-person meetings every year. CEJA believes that allegations of harassment should be dealt with as close as possible to the time of the event by a body able to convene on an ad hoc basis. Moreover, the council has reason to anticipate a significant volume of cases, particularly in the current social climate.

Finally, CEJA is concerned as well that in reaching decisions that parties (and their supporters) see as either excessive or inadequate may undermine confidence in the council, to the detriment of both its judicial and policy work.

For these reasons, CEJA respectfully requests that H-140.837(3), "Disciplinary Action," be reconsidered.

RECOMMENDATION

The Council on Ethical and Judicial Affairs recommends that the following be adopted and the remainder of this report be filed:

- 1. That provision (3) of H-140.837, "Anti-Harassment Policy" be rescinded; and
- 2. That the process for implementing AMA's anti-harassment policy be referred to the Board of Trustees for further study.

5. PHYSICIANS' FREEDOM OF SPEECH (RESOLUTION 6-I-17)

Reference committee hearing: see report of Reference Committee on Amendments to Constitution and Bylaws.

HOUSE ACTION: RECOMMENDATIONS ADOPTED RESOLUTION 6-I-17 NOT ADOPTED REMAINDER OF REPORT FILED

At the 2017 Interim Meeting the American Medical Association (AMA) House of Delegates (HOD) referred Resolution 6-I-17, "Physicians' Freedom of Speech," brought forward by the Minority Affairs Section. Resolution 6-I-17 asked the AMA to "encourage the Council on Ethical and Judicial Affairs (CEJA) to amend Ethical Opinion E-1.2.10, 'Political Action by Physicians'," by addition to read as follows:

Like all Americans, physicians enjoy the right to advocate for change in law and policy, in the public arena, and within their institutions. Indeed, physicians have an ethical responsibility to seek change when they believe the requirements of law or policy are contrary to the best interests of patients <u>and community health</u>. However, they have a responsibility to do so in ways that are not disruptive to patient care.

Physicians who participate in advocacy activities should:

- (a) Ensure that the health of patients is not jeopardized and that patient care is not compromised.
- (b) Avoid using disruptive means to press for reform. Strikes and other collection actions may reduce access to care, eliminate or delay needed care, and interfere with continuity of care and should not be used as a bargaining tactic. In rare circumstances, briefly limiting personal availability may be appropriate as a means of calling attention to the need for changes in patient care. Physicians should be aware that some actions may put them or their organizations at risk of violating antitrust laws or laws pertaining to medical licensure or malpractice.
- (c) Avoid forming workplace alliances, such as unions, with workers who do not share physicians' primary and overriding commitment to patients.
- (d) Refrain from using undue influence or pressure colleagues to participate in advocacy activities and should not punish colleagues, overtly or covertly, for deciding not to participate.

Furthermore, physicians:

- (e) Should indicate they are expressing their personal opinions, which are guaranteed under the First Amendment of the U.S. Constitution, and should refrain from implying or stating that they are speaking on behalf of their employers;
- (f) Should be allowed to express their personal opinions publicly without being subjected to disciplinary actions or termination.

Testimony supported the spirit of this resolution; however, concerns were expressed regarding the appropriate wording of the additional clauses offered by the author.

AMA ETHICS POLICY

As Opinion E-1.2.10 indicates, the AMA *Code of Medical Ethics* recognizes that physicians have a right to advocate for change in law and policy, and indeed have a responsibility to do so when existing law or policy is contrary to patients' interests, a responsibility codified in Principle III of the <u>AMA Principles of Medical Ethics</u>, which states, "A physician shall respect the law and also recognize a responsibility to seek changes in those requirements which are contrary to the best interests of the patient."

The *Code* also recognizes that we have the right to communicate our personal political views to patients and patients' families, within the constraints set out in Opinion <u>E-2.3.4</u>, "Political Communication."

Similarly, the *Code* recognizes our right to due process in disciplinary actions and decisions regarding credentialing and privileging in Opinions E-9.4.1, "Peer Review and Due Process"; E-9.4.3, "Discipline and Medicine"; and E-9.4.4, "Physicians with Disruptive Behavior," all of which prohibit unwarranted or malicious action against physicians.

In Opinion E-2.3.2, "Professionalism in the Use of Social Media," the *Code* recognizes that "participating in social networking and other similar opportunities can support physicians' personal expression, enable individual physicians to have a professional presence online, foster collegiality and camaraderie within the profession, provide opportunities to widely disseminate public health messages and other health communication." However, E-2.3.2 also cautions physicians to be aware that "actions online and content posted may negatively affect their reputations among patients and colleagues, may have consequences for their medical careers (particularly for physicians-in-training and medical students) and can undermine public trust in medicine."

Although the *Code* does not, and indeed cannot, dictate the terms of physician employment as such, several additional opinions do address relationships between physicians and the institutions with which they are affiliated, as employees or otherwise. Thus Opinion <u>E-8.7</u>, "Routine, Universal Immunization of Physicians," provides that physicians who decline to be immunized must accept decisions of medical staff leadership or other authority to adjust practice activities. <u>E-11.2.3</u>, "Contracts to Deliver Health Care Services," calls on us to carefully review the terms of contracts

and "negotiate modification or removal of any terms that unduly compromise physicians' ability to uphold ethical standards," while <u>E-11.2.3.1</u>, "Restrictive Covenants," holds that we should not enter into agreements that "unreasonably restrict" our right "to practice for a specified time or in a specific geographic area on termination of a contractual relationship."

ACTIONS AGAINST PHYSICIANS' LICENSES OR EMPLOYMENT

The Federation of State Medical Boards does not systematically track violations of online professionalism, but a 2012 survey indicated that medical and osteopathic boards have acted against physicians for violating patient privacy or professional boundaries, and other unprofessional or offensive conduct online [Greyson et al 2012]. Researchers found at the time that the total number of actions was small but observed that "this is likely to change as the use of social media continues to grow."

Information about termination or other actions taken against physicians by their employers is limited primarily to media accounts of individual cases [Advisory Board 2011, Canosa 2016, Anderson 2018]. Publicly reported incidents involve both patient-related issues, such as violation of confidentiality, and offensive personal conduct, such as racist speech [Canosa, Anderson].

FREEDOM OF SPEECH

Although constitutional protection for "freedom of speech" is often invoked as an argument against disciplinary action by employers, it is important to note that this concept does not apply to private places of employment. The First Amendment "limits only the government's ability to suppress speech" [Cox 2015].

Private employers generally have the power to terminate an employee because of the employee's speech. For example, Thomas Jefferson University Hospital noted in a statement regarding the hospital's decision to dismiss a nurse for a racially charged post,

An employee's decision to post inflammatory comments on social media is an unfortunate choice and one that is not tolerated at Jefferson.... Whether we choose to acknowledge it or not, we must recognize that what we say on social media can directly affect how people perceive Jefferson—particularly when those comments put into question Jefferson's commitment to the care of our patients, treatment of our fellow colleagues and education of our students [Craig].

Protections for an employee regarding their speech in the private workplace, are possible, but come from outside of the sphere of constitutional law. Instead such protections may be found in contract and employment law. For example, common law analysis of the standard "employment-at-will" doctrine (where an employer can terminate an employee at any time for any reason), provide for exceptions, such that employers may not "contravene public policy" or that employers must act in accordance to an "implied convent of good faith and fair dealing" [McGinley 2012]. Or an employer may simply have an employment policy or agreement that outlines acceptable speech, providing an employee with contract remedies. These possible speech protections are sourced from contract and employment law, illustrating that "freedom of speech" in the private workplace is an employment law issue, not a constitutional rights issue.

CONCLUSION

In CEJA's view, the situation of physicians who express personal views on political and social issues online is importantly like that of physicians who participate professionally in the media. We should recognize that even when we speak personally, we are likely to be viewed by the public through the lens of our professional status and our relationships with health care institutions and should not conduct ourselves in ways that are likely to undermine trust in our profession or health care institutions. As Opinion E-8.12, "Ethical Physician Conduct in the Media," observes, physicians in the public sphere "should be aware of their ethical obligations to patients, the public, and the medical profession; and that their conduct can affect their medical colleagues, other health care professionals, as well as institutions with which they are affiliated."

CEJA concludes, thus, that in its present form, the *Code of Medical Ethics* provides appropriate guidance with respect to physicians' rights to express ourselves on matters of social and political importance and underscores our right to due process when our conduct is subjected to disciplinary review.

RECOMMENDATION

For the foregoing reasons, the Council on Ethical and Judicial Affairs recommends that Resolution 6-I-17, "Physicians' Freedom of Speech," not be adopted and the remainder of this report be filed.

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