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THE JOHN J. LYNCH, MD CENTER FOR ETHICS

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ROUNDING WITH THE EDITOR

Justified Deception, Transition Care, Moral Distress, and Appropriate Access

Evan G. DeRenzo, PhD

Dear Readers,

Welcome to Volume 11, No 3, of the *Journal of Hospital* Ethics (JoHE). In this issue we offer a provocative piece on the ethical justification of deceptive information being intentionally included in a patient's medical record, then an article on pediatric-to-adult transition care (a topic few have considered), a paper focused on moral distress written at a depth that has been needed for some time, and close with a case analysis that returns to the topic of medical records, this time in reference to the appropriateness of surrogate access. Each offers rich material for reflection and I'll address the articles in the order in which they appear.

First, when we think about truth-telling in medical ethics, for the most part, this is a well-established standard. Like our first author, Appel, I shan't address the literature that establishes this norm other than to say that in order to make sense of Appel's article one should already be familiar with a strong consensus for telling the truth. This truth-telling consensus, also, can be assumed to extend to not only communicating with patients and families, but to being truthful in chart documentation. Further, to make Appel's piece sensical, one has to accept his claim that charting deceptively "…is both relatively common and acceptable to many providers…" For purposes of my comments here, I'll accept this claim and move forward.

Appel writes convincingly and cogently about the many scenarios in which a provider might be inclined to be less then punctiliously truthful in a patient's chart. He then presents his three-part framework for deciding whether there is either strong or weak justification for deceptive chart documentation. The framework is organized into three (3) sections: patient preferences, patient welfare, and systemic injustice.

Having selected the ethical principles of autonomy, beneficence, and justice in which to ground the framework, this array of ethical principles provokes thoughts of other possible principles that might be substituted. For example, one could substitute integrity, fidelity, and accountability. Or one could substitute community, non-maleficence, and loyalty. A final example, brought to mind by the timeliness of the religious celebration of Christmas, includes virtues of faith, hope, and charity. Regardless, this article presents a wonderful opportunity to consider how different ethical principles might map onto Appel's framework.

Another, broader, intriguingly provocative set of questions raised by this paper includes, "What does it mean to be meticulously truthful in documentation?" Any answer to this question presupposes one has the answer to another question, "How does one know that what one sees in a patient on a subjective scale of mild to severe meets these severity markers accurately?" Further, "What might 'accurately' mean when assessments are subjective?" and "Might one's own experiences influence a provider's subjective assessments?" One could go on and on flipping various ethical principles throughout Appel's paper. And the additional questions the paper raises are probably unanswerable in any definitive sense. But even if one is firmly wedded to a principle of honesty, an open mind coupled with rich clinical experience makes this article tantalizing. In an era of 'alternative facts,' it's sometimes difficult know what truth is.

Our second article might strike some of our readers as outside JoHE's normal lanes. But after thinking about it for a while, one comes to appreciate the importance of the issues raised. We, for instance, at the Lynch Center for Ethics, work in an adult, acute care hospital. Our next-door neighbor is Children's National Hospital. It is quite likely that as the chronically ill children age-out over there, many are likely to be transitioned into care with us. That realization made me only too aware that the kind of program for which this article advocates is missing at our hospital, and we could benefit mightily from having something like it here.

When the Human Immunodeficiency Virus (HIV) was first being seen, especially in children, I was in my fellowship in bioethics at the National Institutes of Health (NIH). We noticed quickly that these children were quite different from children in many other pediatric NIH studies. Particularly for the roughly 7-year-old to 15-year-old

group who had become infected during birth and had been in the health care system chronically since then were, for example, far more educated about health care and the health care system than their non-chronically ill peers. Because there was still much fear over the transmissibility of the virus, these children often showed maturity far beyond their years related to how they were cared for in the research setting. Often, it at least seemed to me, that the decision-making of these children was advanced well beyond that of many of the adults around them.

As I reflect on those years and those children, I can imagine them aging-out of their care or research studies at Children's National and coming to us at MedStar Washington Hospital Center. I'm sure if we received training in the care and management of children aging-out of pediatric research and clinical care into the world of adult medicine, these patients would receive treatment far improved compared to what they would receive without some specialized training of adult medicine clinicians. A little education with smart and sensitive providers goes a long way, especially for specialized patient populations like children with chronic diseases who are transitioning from their pediatric hospitals.

Our third article is on the importance of knitting through leadership attention to ultimately preventing moral distress in a healthcare institution. Over the last few years, there has been much ink spilt over various aspects of the buzzy concept of moral distress – some useful, some not so much. And the task these authors have set for themselves is a particularly tall order indeed. That being said, I have yet to read anything on the subject so broadly and deeply written as is this paper. More personally, as someone who during the development of the field of bioethics advocated for hospitals building strong ethics consultation services as the road to integration throughout a hospital, this paper not only advocates similarly but goes beyond anything I could have imagined, it sort of takes my breath away. Here, Westling, Reeves, and Nelson not only provide a blueprint for working top-down, as well as bottom-up, but ultimately throughout every corner of the institution in order to integrate an attention to ethics and prevention of moral distress to the greatest degree reasonable.

I think many of us never really believed such a day would come, but this paper is not only a blueprint, it is a blueprint in which each 'room' is already furnished with plumbing and electrical. To my mind, implementation of the Moral Distress Mitigation Assessment is the epitome of the Learning Health System's (LHS) approach (explained in their paper) to constructing ethically sound healthcare environments. As you read the paper, see if you think you can add anything more to this assessment? It seems to me that any hospital that seriously puts all aspects of this assessment to work in their institution, while never preventing all ethics conflicts or avoiding anyone ever feeling moral distress, certainly can say they did everything reasonable to produce such outcomes. I can only believe that such an environment would be providing – assuming superior technical skills of, and common decency in, the clinicians – patient care we would all find excellent.

Our fourth and last article addresses challenges in satisfying standards for adequate disclosure and the appropriateness (justifiability) of allowing surrogate access to a patient's medical record via a classic case analysis. How much (quantity) and what type of information (content) to disclose in order to meet those standards becomes inherently more complex with surrogates given a team's responsibility to balance an adequate disclosure with an appropriate protection of the patient's privacy. As Meurer and Bertino argue, in many instances the access to particular information requested by a surrogate is simply not required in order to make an informed decision.

Moreover, clinical teams may be concerned about revealing too much information to a surrogate, potentially damaging the therapeutic relationship between patient and clinician should the patient regain the ability to participate directly in decision making. Requests for this kind of access, or to any information not deemed relevant to the care options at hand are often well-intended. Given this, teams need to approach limitations to such access compassionately. As one solution, practicing a more conservative standard of disclosure in cases involving surrogates may be justified. (One can only imagine the conversations that would need to be had if and when a clinician felt appropriate in allowing surrogate access to a medical record that included deceptive information as is discussed in our first article.)

Finally, I'd like to turn your attention not to an article published in the journal but to a research study in which JoHE appears elsewhere. That is, in Bobier, Rodger and Hurst's study of artificial intelligence (AI) policies in bioethics and health humanities journals,[1] the results of which showed the need for bioethics and health humanities journals to have explicit policies about the appropriate use and disclosure of AI. Without such explicit policies, it makes it difficult for authors to know

whether they can use AI in preparation and submission of a manuscript, and if submitting to a journal whose standards allow AI use, what kinds of AI use are acceptable, e.g., only grammar and readability, generation of summaries, or the more substantive parts of a manuscript.

Of the 50 bioethics journals studied, only 8 (16%) had an identifiable AI policy statement, including JoHE. Nonetheless, there was little consistency even among those journals that had explicit statements. And of those journals without explicit policies, most were in discussions of what their developing policies should look like, which brings me to my last point about AI for this issue. These policies run the gamut from not permissive to quite permissive. Our policy, which is not permissive, was discussed at our last JoHE Editorial Advisory Board meeting this past summer. During that meeting, there was discussion of whether we might add some elasticity into the policy. We are beginning to plan for a future meeting at which we shall continue and deepen this conversation. If you have any thoughts on this matter, please email them to us at ***johe@medstar.net.*** We would very much like to hear from you.

And with that, we here at JoHE wish you a very happy and safe holiday season.

Sincerely,

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FEATURES

Just Lies:
An Ethical Framework for Deception in the Medical Record

Jacob. M. Appel, MD, JD, MPH, HEC-C

ABSTRACT: The use of deception in the medical record is a highly controversial issue that remains the subject of ethical debate. Considerable scholarship addresses truth-telling in the physician-patient relationship; in contrast, deceptive charting, which raises a distinct set of issues, has received relatively less attention. In particular, except for rules proposing outright proscription, no guidelines or model exists for when to deceive. This paper offers a framework for clinicians grappling with whether, and when, such deception is ethically permissible. Relying upon three factors (whether the deception supports a patient's wishes, whether it benefits that patient's well-being, and whether it helps reverse a systemic or structural injustice) this paper seeks to help guide physician decision-making in a highly fraught area.

KEYWORDS: Truth-telling, patient deception, deceptive charting, medical records, patient well-being

Honesty is widely regarded as a "fundamental" aspect of "modern medical professionalism."[1] Truth-telling serves a crucial role in the physician-patient relationship, ensuring that individuals seeking treatment can trust their healthcare providers. Not only is truthfulness inculcated as a core value early in medical training, but professional organizations such as the American Medical Association, American Board of Family Medicine, American Psychological Association, and the American Nursing Association include the principle of honesty, sometimes referred to as veracity, in their ethics guidelines.[2-5] The acceptable basis for deceiving patients is generally limited to the exercise of therapeutic privilege: the withholding of relevant clinical information when full disclosure would "inflict harm or suffering" without justification.[6] While considerable scholarship examines the ethics of dishonesty during physician-patient interactions, far less has been written about deception in the medical record. Although empirical evidence suggests that such deception is both relatively common and acceptable to many providers, most commentators either condemn the practice or sanction it only under a narrow set of circumstances—such as "gaming" the system to deceive third-party payers into covering necessary care.[7-10] For the clinician seeking guidance on whether to engage in deceptive charting, and under which circumstances, no systematic framework currently exists for such decisions. To address this gap, what follows is a proposed model that incorporates three relevant variables: whether a physician is acting in accordance with a patient's wishes, whether a physician's deception furthers the patient's welfare or the physician's own, and whether the context in which the deception occurs is likely to produce a just outcome independent of the deception.

Deceptive charting can take many forms. For instance, a physician might knowingly document false information in the medical record—such as fabricating a diagnosis to ensure insurance coverage for an idiosyncratic choice of medication. More often, deceptive charting will occur in subjective clinical assessments. Physicians frequently make patients appear sicker on paper than they are to ensure continued insurance coverage for hospital stays. Physical therapists may exaggerate a patient's prospects for recovery to secure a spot in an acute rehabilitation facility. Similarly, social workers may downplay a patient's substance use history to increase the likelihood of securing services for which that patient might otherwise be ineligible. At other times, clinicians will engage in deception by omission, neglecting to note relevant information that a reasonable provider would be expected to report. For instance, a physician might not document a recent episode of agitation if doing so could compromise a patient's prospects for nursing home placement. These examples reveal the diverse manifestations of deception and the ethical complexities they raise.

The model proposed here does not distinguish between various forms of deception. Whether one engages in deception by commission or omission may have a bearing upon the likelihood of one's deception being detected. However, the nature of the deception has no logical relevance to the ethics of the action. Presumably, in all forms of deceptive charting, the goal is to deceive so as to achieve a particular end within a particular context. As a result, the fact of the deception, as well as the objective and circumstances, bear on the ethics of the decision. In contrast, the nature of the deception and likelihood of detection do not. To channel Shakespeare, that which we call a lie, by

any other name, would still smell of prevarication.

To Lie or Not To Lie? That Is *Not* the Question

The ethics of deception in medicine have already been addressed extensively in the literature. A range of objections to lying on behalf of patients have been advanced on both "deontological and consequentialist" grounds.[10] For instance, gaming the system can corrode the patient's trust in the doctor, undermine public confidence in the medical profession, divert resources unjustly, and transgress the ethical duties of veracity and respect for law. [11] Tavaglione and Hurst summarized those objections comprehensively in their provocative 2012 article, "Why physicians ought to lie for their patients?"[10] Robert Sade responded to their argument that gaming an unjust system was justifiable by noting an additional, teleological objection to deception: namely, that the physician, in lying, would be "habituat[ed] to deceit in a broader range of circumstances"; this effect, in turn, would prevent the "rationally determined choices and actions" necessary for "human flourishing."[12] These debates are not the subject of this paper and no reason exists to rehash them here. Instead, this paper starts with the premise that some learned commentators object broadly to the practice of deception in medicine while others find the practice acceptable in an array of circumstances. With the acknowledgement that these debates are likely to continue, this paper seeks to offer guidance to those clinicians who have already embraced the case for duplicity—and deceptive charting—at least some of the time. For those clinicians who believe honesty is always the best policy, this paper likely offers no more of value than ethical guidelines for moral turpitude—a concept both paradoxical and absurd. In other words, this paper seeks to be a map rather than a missionary tract.

The Relevant Variables

The framework proposed here incorporates three specific factors that a clinician should consider prior to engaging in deceptive charting: patient preference, patient welfare and systemic context. While no factor alone is necessarily dispositive, each should play a role in the provider's decision. The factors are discussed further below.

Patient Preference: The first factor to consider when deciding whether to engage in deceptive charting is whether one's actions accord with the patient's preferences. In some situations, the provider may feel comfortable asking the patient directly if that patient is comfortable with the provider engaging in such a deception. This paper refers to that as a process preference. More often, the clinician will not ask the patient to approve the deceptive documentation—either because the patient lacks capacity to engage in such a discussion or because doing so, in the clinician's opinion, will likely burden the patient unnecessarily. Instead, the clinician and patient will agree upon a desired outcome, such as continued hospitalization or placement in a skilled nursing facility, and the clinician then will engage in deceptive documentation to achieve this outcome. This paper refers to that as an outcome preference. The core bioethical principle of autonomy argues strongly in favor of prioritizing both process preferences and outcome preferences in the absence of a competing value.

Patient Welfare: The second factor to consider when deciding whether to engage in deceptive charting is whether one's actions are intended to serve the patient's welfare or one's own. In many cases, the patient will be unable to express a preference due to impairment. Yet at other times, the patient's preferences will not reflect what the provider perceives to be the patient's best interests. For instance, a recently suicidal patient may seek discharge from a psychiatric facility, while the mental health provider may still believe the patient to be at high risk of self-harm. Such a provider might engage in deceptive charting to justify holding the patient further on an involuntary basis, even submitting such documentation to a court to ratify such a decision. That action clearly defies the patient's preferences. At the same time, the provider—whether accurately or not—believes he is acting in the patient's interests. Serving the patient's welfare through deceptive charting reflects the core bioethical value of beneficence.

In contrast, cases will arise in which the provider overtly engages in deceptive documentation to serve the provider's own interest. Sometimes, the impact upon the patient will not prove significant—such as using a specific diagnosis in the chart to increase the likelihood of insurance reimbursement. In other cases, the patient may be negatively impacted. For instance, a social worker might downplay a history of substance abuse to expedite discharge to a facility the patient opposes or when the patient feels unready to leave. Often, liability concerns will lead to self-serving, deceptive documentation. A psychiatrist, for instance,

might not document provocative threats of harm by a patient believed to be malingering who is discharged from the emergency room in order to reduce the psychiatrist's own exposure to liability.

Systemic Context: The third factor to consider when deciding whether to engage in deceptive charting is whether one does so to overcome an injustice in the social context. For instance, one might choose to chart deceptively to ensure patient access to a particular medication if that drug were the only appropriate therapeutic choice, but the insurance company has acted unreasonably in previously refusing to pay for it. Needless to say, large numbers of patients face challenges as a result of unjust structural forces: lack of prior access to medical care, living in food deserts, discrimination in housing, etc. How unjust the context must be, and how directly that injustice must link to the difficulty that the deceptive charting seeks to overcome, will prove highly subjective. Arguably, no existing healthcare system is perfectly just. However, engaging in deceptive charting to secure a patient placement in a nursing facility may prove less acceptable in systems in which those beds are allocated relatively fairly as opposed to systems in which allocation primarily reflects power and privilege. Using deceptive charting to overcome inequities or injustices in the structure of healthcare, such as biased insurance practices, reflects the core bioethical principle of justice.

The Framework

This paper proposes considering the three variables in sequence when a physician contemplates whether to engage in deceptive charting. Of note, many situations will arise in which a physician does not consider such deceptive conduct at all—because doing so would violate the physician's own morality or perceived sense of duty. This framework is not applicable in such circumstances. In other words, the framework is not designed to create an ethical duty to engage in deception in contravention of the provider's values, but rather to guide them when doing so *is* consistent with their own values. First, when contemplating deceptive charting, the clinician ought to consider the patient's preferences. In cases where the physician consults the patient and the patient expresses a process preference that favors an outcome preference best achieved through deceptive charting, the case for such deception is arguably strongest. In contrast, should the physician consult the patient and the patient expresses a process preference that opposes deceptive charting, even if also favoring an outcome likely to be achieved by deception, a very strong case exists for deferring to the patient and charting honestly. A strong argument also exists for honest charting if the patient has not been consulted, but other evidence suggests that the patient would oppose deception. For instance, the physician might reasonably infer objection if the patient had opposed similar deceptive practices in the past. In most cases, of course, the physician is unlikely to consult the patient at all about their preferences regarding deception for a range of legitimate reasons. In particular, a conscientious physician might not wish to place the psychological burden of such deception upon a patient. Under such circumstances, the physician may choose to rely upon the patient's outcome preference alone. In the absence of a compelling argument against honoring the patient's autonomy in such circumstances, respecting the patient's preferences appears ethically justified.

Second, when contemplating deceptive charting, the clinician ought to consider the patient's interests. Needless to say, should the patient's preferences already favor deceptive charting, then if doing so will also further the patient's well-being, this concordance establishes an even stronger case for doing so. More complicated are cases in which the patient's outcome preferences do not accord with the physician's views of the patient's interests. Such cases involve overriding a patient's preferences, often in areas where the law has explicitly placed such decisions in the hands of the patient. For instance, many jurisdictions do not permit a psychiatrist to hospitalize a patient suffering from alcohol use disorder against that patient's will for treatment of substance use—even if the patient stands at high chronic risk of dying from excessive alcohol consumption. If such a patient presents to the hospital emergency room intoxicated and expresses suicidal intentions while under the influence of alcohol, but later recants those intentions when sober and seeks discharge, a psychiatrist might intentionally not document the retraction and instead use the statements as a basis for involuntary hospitalization. Under these circumstances, the patient's outcome preferences and likely well-being are at odds. The case for deceptive charting here is weaker than when the patient's outcome preferences and interests are concordant. The case is arguably weakened further by the fact that society has weighed in on this question and established an ethical standard that the clinician, through deceptive charting, seeks to

override.

At the same time, the argument for deceptive charting is much stronger than in cases where the patient objects to a particular outcome and the outcome also does not further the patient's interests. For example, unlike in the scenario above, a patient without a history of alcohol use disorder might present to the hospital emergency room intoxicated and express suicidal intentions while under the influence. If that patient later recants those statements when sober and seeks discharge, a psychiatrist might intentionally not document the retraction and instead use the statements as a basis for involuntary hospitalization—but for reasons other than ensuring the safety of the patient. For instance, the psychiatrist may fear liability if the patient does commit suicide while intoxicated at a future date and may believe that hospitalizing the patient involuntarily will shield him from such liability. Or the psychiatrist may be under pressure to fill hospital beds to increase reimbursement for his employer—thus ensuring the financial stability of the hospital to keep psychiatrist services available for other patients. In the first scenario, the physician is acting out of self-interest; in the second, out of concern for society. Yet in both cases, the well-being of the patient is not served—and likely harmed. In such cases, the ethical justification for deceptive charting is extremely weak.

Third, when contemplating deceptive charting, the clinician ought to consider the structural context in which the situation arises. Stronger arguments exist for engaging in deceptive charting when one does so to reverse existing injustices that are directly linked to the patient's current predicament. In a truly just healthcare system—for example, one in which resources are allocated equitably—deception is harder to justify because honest documentation should result in the patient receiving the care their condition deserves. In fact, deception might lead to injustice by causing resources to be diverted from those most deserving. For instance, overstating impairment to secure nursing home placement for an indigent, elderly patient who has no other place to live would be far easier to justify than doing so in a society where the state guarantees safe housing for senior citizens. Of course, since no known healthcare system is perfectly just at present, this reasoning might be used to excuse any and all deceptions that further social justice. To prevent the principle from becoming unwieldy or impossible to apply, clinicians should give greater ethical weight to circumstances in which the specific injustice and the need for deception are closely linked. Ultimately, physicians should consider whether the deception serves to redress a particular structural harm that directly affects the patient's care, or whether they are merely favoring their patient at the expense of others in a way that makes the system even more inequitable. When deceptive charting stems from a desire to achieve a just outcome, rather than merely serving a particular interest, its ethical justification is substantially stronger.

Eight possible situations arise under this framework. **Table A (page 151)** offers a description of each, as well as examples and guidance.

Implementation

Several potential challenges are likely to arise in the use of this model. Some of these concerns are intrinsic to deceptive charting more broadly. First, false documentation—if proven—may raise legal liabilities for the clinician. Some forms of deceptive charting, such as lying to insurance companies, may constitute criminal fraud. Other instances may lead to medically negative outcomes, such as when another provider takes a false statement at face value, leading to litigation by the very patient the deception was intended to benefit. Deceptive charting may also create liability for one's employer and even one's innocent colleagues. Second, in the absence of acting in accordance with known process preferences, a clinician risks having a patient discover the deceptive charting—and losing trust in the physician as a result. Patients might infer that a physician who lies to insurance companies and rehabilitation facilities will also lie to them. Alternatively, the patient may conclude that deception is a necessity, and even a norm, in healthcare, leading to further deception in cases where such dishonesty is not justified. Fourth, the risk exists that some clinicians will engage more broadly in deceptive charting than others; as a result, rather than furthering equity, deceptive charting may reflect bias and exacerbate inequities in resource allocation. Finally, not addressing injustices head on creates a structural danger in that "workarounds" may enable policymakers to avoid systemic change.

The framework also has several vulnerabilities of its own. As a general rule, clinicians are encouraged to outline the reasoning behind their decisions in the medical record. Doing so protects against liability and keeps other clinicians informed of the decision-making rationale. Unfortunately, since deceptive charting is generally neither legal nor consistent with formal hospital poli-

Table A: Ethical Evaluation of Deceptive Charting Scenarios Based on Patient Preference, Patient Welfare, and Systemic Context

Ethical Principle Supported	Example	Guidance
Autonomy & Beneficence & Justice	An unbefriended elderly patient with impaired mobility after a stroke wishes to be placed in an inpatient rehabilitation facility. Her physician, believing such placement is in her best interest and knowing that her insurer typically denies such placements, exaggerates her limitations to secure approval.	Strongest ethical justification. Deception aligns with the patient's preference, promotes her welfare, and counters an identifiable systemic injustice.
Autonomy & Beneficence	A woman with a progressive neurological disorder wishes to remain at home for end-of-life care. To ensure approval for hospice services typically reserved for cancer diagnoses, the physician exaggerates her functional decline in the chart.	Strong ethical justification. Deception supports both the patient's goals and well-being, though not explicitly motivated by structural injustice.
Autonomy & Justice	A lesbian couple seeks fertility treatment but is denied Medicaid coverage on the basis of their sexual orientation. With the patient's consent, the physician codes the procedure as though the couple were of opposite genders.	Strong ethical justification. Deception aligns with the patient's preference and targets overt systemic discrimination.
Beneficence & Justice (Patient's preferences unknown or patient indifferent)	A nonverbal child with asthma is repeatedly hospitalized due to exacerbations. A physician documents a mold as a likely trigger, and a resulting seizure, to qualify the child for emergency housing in a neighborhood with cleaner air.	Some ethical justification. Deception promotes the child's welfare and addresses a housing-related systemic injustice. Autonomy is not a factor due to incapacity.
Beneficence & Justice (Patient overtly objecting)	A psychiatric patient is not acutely dangerous, but experiences psychotic mania and risks doing damage to personal relationships and financial well-being. The psychiatrist documents the patient as dangerous to prevent discharge.	Ethically problematic. Deception encourages an outcome that the law specifically proscribes.
Autonomy Only	A patient with advanced CHF insists on being discharged home despite poor functional status. To support the discharge, the physician downplays limitations in the chart, despite believing home discharge is medically inadvisable.	Limited ethical justification. The deception furthers autonomy but does not serve the patient's welfare or address structural injustice.
Beneficence Only	A patient with refuses care for type-II diabetes. Believing the patient lacks insight, the physician exaggerates confusion to the courts in order to initiate treatment.	Limited ethical justification. Promotes the patient's welfare but overrides their autonomy and is not rooted in justice. Requires scrutiny to avoid paternalism.
Justice Only	A homeless patient with chest pain of unknown cause is admitted to the hospital. Though the patient did not seek care and has no acute medical need, the physician documents unstable angina to extend hospitalization and avoid unsafe discharge.	Limited ethical justification. If the patient actively objects to remaining, arguably very weak ethical justification.
None	A psychiatrist embellishes a patient's psychiatric symptoms to justify continued admission, primarily to increase institutional revenue. The patient objects to the admission, derives no benefit, and faces no structural barrier to discharge.	Not ethically defensible. Deception serves institutional interests only, undermines all three core principles, and erodes trust in the medical record and in the profession.

cies, clinicians cannot discuss the use of the framework in the medical record. Even explaining its use to other providers or to house officers orally may invite objections and risk legal consequences. The result is that the clinician may use the framework as a tool to shape personal thinking, but not necessarily as one to persuade colleagues.

Another related challenge with the framework is that, even with this approach, few cases are likely to be clear-cut or to fit neatly into categories. Rather, many ambiguous situations will arise. Clinicians will also be asked to engage in complex, values-based choices such as weighing short-term versus long-term well-being or deciding whether a particular act of deceptive charting is proportionate to the related injustice. Usually, in medicine, such questions are answered through consultation with colleagues. The hope is to triangulate upon a consensus approach—which, incidentally, mirrors the structure of many hospital ethics committee deliberations. Such a group input model also takes some of the psychological burden off the individual clinician. However, the illicit nature of deceptive charting renders such consensus building virtually impossible.

Conclusions

The goal of this paper is not to champion deception in medical documentation. Leading scholars have advanced a range of views on this fraught subject from nearly absolute rejection to acceptance as a tool for social justice. For clinicians opposed to deception under all circumstances, the arguments presented here are likely anathema. However, for the many physicians who do not see the morality of truth-telling in absolute terms, this three-factor framework offers a means for analyzing clinical cases. When patient preference, patient welfare, and systemic justice align, the case for deceptive charting becomes most compelling. As they diverge, the justifications for such conduct prove less convincing. Ideally, clinicians will have to draw upon this framework rarely and as a matter of last resort. In the long run, the hope is that a more just healthcare system will render many acts of deception unnecessary. In the interim, however, providers are likely to struggle with when to embrace dishonesty. To the degree that they choose to do so, they should act with open eyes and a firm understanding of the factors and tradeoffs involved.

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Interactive Awareness-Raising Workshops About Transition Care for Pediatric Patients Moving to Adult Healthcare Environments

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ABSTRACT: Background: Transition designates the process by which youths with chronic conditions migrate to adult healthcare. There are important and consequential clinical challenges in this period which have led to the development of transition programs. This period also evokes ethical issues about human flourishing (e.g., exercise of autonomy, self-acceptance of living with a chronic condition). However, awareness about these clinical and ethical issues is still lacking. Methods: We developed an interactive awareness-raising workshop about transition. The one-hour workshop comprised three parts: (1) information on the existing institutional transition program; (2) information about local research data collected on transition care and from which this workshop study stems ; (3) semi-structured discussion on the avenues for reflection and action in relation to the research results presented and the tools and support offered by the institutional program. Data were gathered through a short online evaluation survey to assess form and content of the workshop and field notes grasping workshop contributions, promising practices, and courses of action and mobilization. 88 participants were recruited in 10 clinics. Results: The workshop was positively evaluated with respect to information provided, support for discussion, and improving practices. Four main learnings were reported including a need for better transition structure, information, preparation, and coordination as well as the recognition of barriers and challenges in transition. Main ideas to improve practices included structural changes and policy improvements. Conclusion: Results support the value of interactive workshops and participatory knowledge mobilization in the context of transition care, human flourishing, and ethics more broadly.

KEYWORDS: Transition care, Bioethics, Chronic Illness and Disability in Youths, Human Flourishing and Deliberative Wisdom, Organization of Health Services

Introduction

Today, the term 'transition' may refer to various kinds of experiences and medical care. In this paper, transition care designates the process by which youths with chronic conditions migrate to adult healthcare when reaching adulthood, often at age 18.[1,2] The literature has documented important (e.g., lack of communication, lack of coordination in out-patient and in-patient settings) and consequential challenges (e.g., suboptimal clinical management, loss of patients) in this period.[3,4] This had led to the development of dedicated transition care and transition programs.[5] The evaluation of the efficacy of such encompassing intervention programs is growing [5-8] while there are concerns about their sustainability.[9] One of the underlying issues impeding progress is the lack of awareness of how transition deeply affects youths and the role that healthcare professionals have in practically and ethically supporting adaptation in this context.[10] For example, adult pediatric professionals have a responsibility of engaging youths in age - and developmentally-appropriate information sharing and decision making to help them prepare for adult life and adult healthcare.[1-3] Moreover, transition programs are often designed from the standpoint of clinicians in ways that do not squarely meet with the values and trajectories of youths with chronic illnesses but bridging this gap is a promising strategy.[11,12] For example, transition programs tend to focus on clinical management and independence while many youths do not project through these values and envision another path to their flourishing because of their inability to live fully independently.[13,14] Transition is also not well covered in the standard medical curriculum, thus creating a need for ongoing education and for transition program development oriented by values and aspirations of youths and families.[12,15,16]

Far from being solely an important clinical period, transition to adulthood and transition care is ethically charged. From the standpoint of a developmental perspective and of human flourishing (a.k.a. *eudaimonia* in ancient philosophy), the period of transition is one where youths are called upon to exercise their autonomy and participate in decisions about their self-management and their medical appointments. It is also a period of identity development.[17] Living with a chronic condition induces important differences in life trajectory which impact how youths come to accept who they are and what their strengths and challenges are.[13,14] Adolescence and young adulthood are also a period of change in human relationships. For example, peers play a significant role in defining one's identity and life interests, but friendships and intimate relationships can be complicated by chronic illness.[18,19] Youths typically desire to take

distance from parents and become independent, but the literature shows that parents of youths with chronic illnesses tend to be over protective, especially when they are stressed,[20] leaving less freedom for experimentation. At the same time, autonomy tends to be viewed as relational (relational autonomy) in youths with chronic conditions. They desire ongoing involvement of their parents in their care,[21,22] counter to a view rooted in pure autonomy. All these ethically salient issues are poorly addressed in current transition literature.[23]

The substantial issues that youths face in transition care led us to adopt a theoretical lens rooted in human flourishing and geared toward action. The concept of human flourishing is central to ancient ethics[24] as well as some contemporary ethics theories (e.g., virtue theory; capability theory) which have rejuvenated this orientation. Importantly, a recent body of work in psychology provides empirical footing for this concept. For example, Carol Ryff's influential account of human flourishing includes 6 dimensions: autonomy, self-acceptance, positive relationships with others, personal growth, environmental mastery, and purpose in life.[25] Although this account of human flourishing is not universally accepted, it is an integrative concept built on empirical evidence and theoretical literature. It has proven to be a robust and generalizable tool for various types of research.[26] Building upon this account of human flourishing, a new ethics theory – deliberative wisdom theory – advances the centrality of human flourishing as a positive and constructive orientation for ethics.[27] Rooted in philosophical pragmatism, this theory invites active data gathering and experimentation in tailoring notably healthcare services to reflect the plurality of ways in which patients, including youths with chronic conditions, view their flourishing. It envisions ethics though a cyclical action-oriented learning model where dialogue is proposed as a form of co-learning on human flourishing is, and about which experiences in human life offer conditions and experiences leading to human flourishing.[27] Inspired by philosophical pragmatism, it specifically motivates the use of participatory approaches where those concerned have a voice in determining what a flourishing life is for them and gain efficacy in acting upon their life situations.[27]

As part of a participatory research study inspired by recent scholarship on human flourishing and deliberative wisdom theory and aiming to support the development of a tailored institution-wide transition program focused on transitioning youth wellbeing and flourishing, we developed an interactive awareness-raising workshop about transition care. This participatory method has showed value to address a wide array of topics, notably in ongoing medical education,[28,29] especially when workshops take an interactive format.[30] This workshop aimed to share the results of previous phases of this ongoing study (e.g., a literature review study on transition and human flourishing,[16] an interview-based study on transition care and how youths envision their flourishing therein,[11] a survey-based study on transition care and flourishing,[31] a co-creative study featuring videos cocreated with youths on important dimensions of their flourishing),[32] share progress on the development of an institutional transition program (e.g., available and upcoming clinical tools, resources for youths and families), and nurture further engagement toward action in response to the needs and values of youths and families. Following the participatory orientation of the study, we returned to teams who had participated in the study previously (e.g., survey, interviews) and engaged them, based on our results and an example of video content cocreated with youths. Given the participatory orientation of the study,[33] the workshop was designed to foster a co-learning experience[34] where the presenting clinical and research team was also touring clinical programs to learn, build trust, and glean insights to scaffold an institutional transition program in alignment with the values of youths.

Methods

Workshop Content and Design

The interactive in-person workshop was designed with various complementary goals: (1) raise awareness about transition since this is a topic often still neglected; (2) provide information about transition and thus help inform and train healthcare professionals; (3) present the results o (i.e., a literature review study,[16] an interview-based study,[11] a survey-based study,[31] a co-creative study featuring videos cocreated with youths)[32] of an ongoing project on ethics, transition, and human flourishing in which some clinical teams and some individuals healthcare professionals had participated; (4) evaluate reactions to the content and resources of the Parachute program; (5) help take action about transition, and (6) gather ideas and recommendations for further improvement in transition care. The workshop integrated an overview of both ongoing clinical resources offered through the institution's transition program as well as re-

sults of a participatory project on ethics, transition, and human flourishing. The resulting workshop thus adopted features of both educational and interactive workshops to promote engagement and discussion[30] in the spirit of participatory action research which emphasize how stakeholders need to be involved in developing and enacting action plans.[33]

The interactive awareness-raising one-hour workshop comprised three main parts (see online supplementary material for visual support used).* The first part (approx. 12 minutes) aimed to provide information on the Parachute program at the Centre hospitaller universitaire Sainte-Justine and the resources offered for youths, parents and healthcare professionals (slides 4 to 24). This part was presented by one or two members of the clinical team. The second part (approx. 25 minutes) was intended to inform members of the clinics and programs about the research data collected to date as part of the ongoing participatory Parachute research project (slides 25 to 54). This part was presented by a member of the research team. It included an overview of a literature review conducted at the start of the project,[16] as well as interview[11] and survey data31 from earlier phases of the project which informed on preferences, values, and needs of youths. Participants were also exposed to one of the 6 short videos on transition care cocreated with youths and issued from this same research.[32] The short video on youth-healthcare professional relationships was selected for inclusion given its relevance to this audience and the showcasing of the importance of relational autonomy in line with research results.[11,31] Finally, the third part of the workshop (approx. 20 minutes) was devoted to semi-structured discussion on the avenues for reflection and action in relation to the research results presented and the tools and support offered by the Parachute program. It was moderated by a member of the research or the clinical team, based on availability. The four guiding questions for the discussion were: (1) What do you retain from today's presentation? (2) Do the data shared correspond to your experiences and observations? (3) What practice (s) do you see as promising for supporting young adults (and their parents) in transition? (4) How could the program/unit to which you belong mobilize itself (more) to improve transition support? A QR code leading to the survey (described below) was included at the very end of the PowerPoint presentation. The workshop was developed across several research and clinical team meetings and pilot tested on a general audience prior to data collection.

Recruitment and Consent

Recruitment for workshops was undertaken by a clinical research coordinator who followed up with clinical units and programs who had participated in previous phases of the project and/or had manifested interest in hosting the workshop. A target of 8 to 10 workshops was set based on our goals of assessing the workshop and respecting our timelines and resource constraints. Consent to the workshop and related notetaking was sought through a simplified one-page consent form disclosing the purpose of the study. This process was approved by the research ethics committee since the data were non-identifying and not highly sensitive. Participants were also not obligated to take part in the workshop. They were also free to leave the room throughout the process if they felt uncomfortable. Moreover, they were free not to speak, or to indicate that they would like no notes to be taken on a specific piece of information or comment shared in the discussion. Completion of the short evaluation survey was proof of acceptance of participation in the project as permitted by the Tri-Council Policy Statement (official research guidelines in Canada) since no sensitive information was collected and no identifying information was requested. A box certifying acceptance of this use had to be checked to access the survey questions. We offered a short description of the project on the survey questionnaire, and communicated information about the project, reiterating the free and voluntary nature of participation and the general purpose of data collection.

Data Gathering

Data about the workshop was gathered through a short evaluation survey as well as field notes. The workshops were not recorded to reduce intrusiveness and foster a constructive, open, and collegial atmosphere.

Appreciation survey: The impact of the interactive awareness workshop was assessed by means of a

* https://www.chusj.org/soins-services/services-connexes/Programme-Parachute/MP/Capsules-video

short appreciation survey (see online supplementary material). Both the impact and usefulness of the workshop for understanding transition issues among young adults were assessed. Respondents were asked to evaluate both the form and content of the workshop (see **Table 1 on page 157** for survey structure). The survey consisted of 10 open and closed questions and took approximately four minutes to complete. It was introduced in the Lime Survey platform of our university as requested by the Research Ethics Board. Questions 1 and 5 were checkboxes; questions 2, 3, 4 and 7 were Likert scales (Scale of 1-9. Value of 1=completely disagree. Value of 9=completely agree) and questions 6, 8, 9 and 10 were open-ended with no character limits.

Field Notes: Structured field notes[35] were taken by a dedicated member of the research team who was not involved in presenting the content of the workshop. The purpose of the notetaking was to gather – without identifying the participants – ideas relating to the main questions posed by the moderator. The structure of the notes included: (1) what people retained from the workshop, (2) promising practices, (3) courses of action and mobilization, (4) other observations as well as a (5) global appreciation of the workshop by participants. The notetaking process was three-fold (taking the notes, correcting them, validating them), and this was done for all 10 workshops by three distinct persons.

Data Analysis and Data Presentation

Answers to the survey which can be quantified are reported using basic descriptive statistics (averages and median). Open-ended answers to the survey were submitted to a basic form of qualitative content analysis.[36] A first coder reviewed the answers and identified patterns to assemble the ideas into broader categories. A second coder reviewed the basic coding scheme and enriched it. Once agreed upon, the coding scheme was applied by the first coder and verified by the second. Consensus was sought between coders. No substantive disagreements occurred in this process. To report this basic qualitative content analysis, the name of the category is reported since it summarizes the essence of the idea.

The field notes were submitted to the same process of qualitative content analysis. In this case, the original categories used for notetaking were used and then merged to regroup relevant content. As a result, the categories for "What people learned" and "Other comments" were merged as well as the categories for "Promising practices" and "Courses of action and mobilization" given their overlap and similarities. Coding followed the same process as described for the open-ended answers of the survey. However, to report the qualitative data, which was more extensive than the survey, synthetic summaries of each category of content were developed by reviewing the relevant coded content. Illustrative examples were pulled out to elucidate the content. The coding categories are found in the tables and result section. All French language content was translated using the free version of DeepL and verified by two bilingual members of the team.

Patient and Public Involvement

The reported research does not involve patients and the public. However, the previously developed videos used during the workshop featuring youth testimonials (reported elsewhere) were co-produced with youths and parents. Furthermore, an advisory committee overseeing the study includes youths and parents (as well as healthcare professionals). It offered advice on the study materials and the design of the study.

Results

A total of 10 clinics were recruited **(Table 1)** composed of 88 participants, in groups ranging from 6 to 13. Global appreciations of the workshops stemming from the observation were mostly positive and generally reflected an appreciation of the challenges of transition and a desire to move towards action. In one workshop, some participants were critical of the approach taken. They saw transition care as being the responsibility of adult practitioners and that too much emphasis was put on pediatric care. In another workshop, participants saw the results of the project as redundant with other initiatives.

Table 1: Information on the Workshops

Participating clinic or program	Date	Number of participants
Adolescent medicine	April 23, 2024	7
Gastroenterology	April 26, 2024	10
Pneumology	May 9, 2024	12
Pediatrics	May 10, 2024	6
Neurology	May 14, 2024	7
Nephrology	May 27, 2024	6
Oncology	May 28, 2024	6
Cardiology	June 3, 2024	10
Hematology (psychosocial service)	June 4, 2024	13
Endocrinology	June 5, 2024	11

Based on the individual survey, the evaluation of the workshop was highly favorable with respect to the information provided, the ability to support discussion, and support for improving practices **(Table 2).** The workshop was recommended to others and the video featured was judged to be of an acceptable length. In terms of the open-ended questions, 27 participants reported specific take-aways such as learning information about transition, notably about existing tools and resources and action items related to earlier engagement with transition preparation. Twenty-three participants identified a change they would want to make such as improving communication and the information given to patients, improving the documentation of transition and strengthen collaboration and resource sharing across clinics and programs.

Table 2: Appreciation and Action Survey Results (Scores are based on a scale of 1-9, with 1 indicating complete disagreement and 9 indicating complete agreement.)

General appreciation questions	N	Average (median)
This information and discussion workshop informed me about the transition.	40	8.2 (8.5)
The workshop enabled me to discuss or reflect on concrete transition-related situations that are likely to arise in my practice.	39	7.87 (8)
The workshop enabled me to think about ways to improve the transition in my practice.	40	7.85 (8)
I would recommend this workshop to other healthcare professionals.	40	8.38 (9)
Questions on the short video		
The video presented was relevant, interesting and of appropriate length.	39	39=yes; 0=no;
If not, **how** could it have been **improved**? (n=4) Workshop could have been shortened (n=1) Include multi-disabled customers (n=1) Further explain some key points (n=1) Increase the volume of the presented video (n=1)		
Open-ended questions		
What I **take away** from this workshop is that... (n=27) There exists several tools to help with the transition process (n=10) There is still a lot of work to be done with respect to the transition process (n=9) The transition must be prepared at an earlier age (n=6) Transition must take into account the empowerment/fulfillment of young adults (n=2)		
One change I plan to make following this workshop is... (n=23) Enhance the information given to patients and communication (n=11) Improve documentation and tools (n=7) Strengthen collaboration and resource sharing (n=5)		
Other comments on this workshop: Only appreciative comments (n=7)		

What People Learnt and Took Away From the Workshops

Four main learnings were taken away from the workshops. First, there was a stated need for better transition structure, information, preparation, and coordination (e.g., adjust the time of transition to youths, information on transition, prepare clinical pathways, inform earlier about the transition, prepare youths for transition, need for adult support, sustainable funding for transition care, ideas for better coordination of care and collaboration between pediatric and adult settings, prepare transition summaries). This could take the form of delaying transition time and advocating that being 18 years old years ago is not the same as it is now, since youths are not as prepared for adult life. Hence, there weas a reported need for flexibility for a delay of 2-3 years, when necessary.

Second, there was recognition of the existence of barriers and challenges in transition (e.g., administrative barriers, inability for adult providers to see youths before 18 years old, lack of sensitivity to young adults in adult care, particularly challenging transition for patients with complex situations, different foci of adult care, age of consent, patients without family doctors). For example, some elaborated on the difficulty of youths in obtaining a family physician and how valuable this could be at the time of transition since adult specialists can be hard to secure and may not offer the kind of more integrated care that the pediatric environment offered. Other concerns involved how to produce effective summaries of patient dossiers that would be usable for other healthcare professionals.

Third, there was the importance of taking into consideration psychological and emotional aspects during transition was underscore (e.g., familiarity and attachment to pediatric environment, inappropriateness of transferring at 18, starting discussions on transition at an age-and development-appropriate time). For example, participants mentioned that adult care physicians come to Ste-Justine to meet them, because young people are comfortable at Ste-Justine. Further, when discussing the ideal length of time to prepare for the transition, they often stated 2 to 3 years before age 18, but for some patients, it should not be too early because they are too unstable, immature or anxious.

Fourth, there was the demand for support for the proposed (and existing) resources and tools (e.g., value of the videos, better coordination of new and existing tools, dedicated space for transition, peer transition community). For example, healthcare professionals found that the videos could really help start the discussion about transition, especially when the length of appointments and waiting times accumulate over several appointments and doctors cannot always take the time to explain everything. With the videos, young people can take in the information in their own time.

Observations on Promising Practices and Courses of Action

Four main ideas were identified to act and improve practices. First, there were suggestions for structural changes and policy improvements (e.g., get inspiration from practices in other countries, create transition spaces, develop a province-wide service for and information about transition, gradual preparation for youths, set a follow-up appointment after transition, publish a paper for Quebec physicians, introduce patients early on the list for adult care). For example, one participant mentioned the idea of a provincial transition office to help disseminate information and coordinate care. Another mentioned transferring not only the patient but also working on transferring the bond of trust to the adult provider. Additionally, a participant mentioned the need for detailed resources on youth transfers to be centralized, and in referring rather than receiving centers because patients can come from anywhere in Quebec. Thus, having transfer resources centralized at Parachute program rather than in each clinic would prevent patients with special illnesses from falling into the void between care structure at the time of transfer. There was also a proposition of creating "transitional spaces" where healthcare professionals could work on these issues with young people and where young people could meet and discuss.

Second, there were proposals for greater interdisciplinary collaboration and knowledge sharing (e.g., improving administrative aspects of transition through filing and forms, transition attestation, involvement of pivot nurses). One example of a measure to ensure collaboration is a transition attestation to be sent to the pediatric doctor that would confirm that the adult doctor has taken charge of the patient. Another example is pivot-nurses writing messages to indicate who has been seen by whom, as it confirms that patients have been taken into care, and to know who has prescribed what.

Third, there was mention of improving the

transition experience for young adults (e.g., adjusting adult care to youths, work with the emotional attachment developed in pediatrics, postpone transition to age 21, secure the name of the new doctor beforehand, schedule an appointment 6 months after transition or an appointment to verify the transition). For example, providing the name of the adult provider would be a small but meaningful step for patients. Another proposed (and used) strategy by one clinic is to schedule an appointment with the youth after their transition but to cancel that appointment if adult care has been secured. Furthermore, the importance of supporting young adults in their transition to a new service was underscored because, although they may have undergone preparation and feel confident with their pediatric professionals, they may be less so with new providers.

Fourth, there was a request for awareness and communication tools (e.g., maintain and raise awareness in each service, develop specific posters with tips, show short videos in waiting rooms, establish lists of resources). For example, one suggestion would be to take advantage of the time spent in waiting rooms to show short videos on transition developed during this project. Another suggestion would be to have a list of useful contacts for healthcare professionals.

Discussion

Transition is still an area of clinical practice and services in need of improvement given the important documented implications of transition for patients and families4. There is an acknowledged need to raise awareness about transition and to educate clinical teams and programs in ways that mobilize them to act and use existing and newly developed resources. However, there is very limited literature on ethical aspects of transition care[23] and a great need to tailor transition care to reflect the aspirations and flourishing of youths with chronic illnesses.[16] Following previous research on ethics, human flourishing and transition in the form of a literature review,[16] qualitative interviews,[11] surveys,[31] and co-created information videos in a pediatric hospital, [32] we went back to clinical teams to report on progress, inform them of new developments of the institutional transition care program as well as the research results on transition care and flourishing. This effort took the form of an interactive workshop to raise awareness of resources about transition and relevant resources and to also build on the momentum gained through a participatory project to help build bridges between various clinical units and programs. The workshop was presented to 10 clinics and programs. Results show – based on results of the survey and field observations – that the workshop content and format was generally highly appreciated as well as the cocreated short video featuring youths. We were also able to generate awareness and movement toward action based on this information in line with the participatory orientation of the study, its alignment with deliberative wisdom theory,[37] and multiple calls for general improvement of transition care.[1-3] Our study shows the value of tackling a complex and institution-wide topic (transition care) using interactive workshops, an educational method in line with recent reviews showing their efficacy.[38]

Integrated, Participatory Transfer of Knowledge

There are few studies about integrated knowledge transfer and participatory knowledge dissemination39 in the context of transition care. There is an understandable common strategy of designing transition programs and implementing them in a more top-down fashion. This study helps fill this gap and shows important positive outcomes of an interactive and participatory workshop in sharing information, raising awareness, and getting an initial impetus for further action. Participants took the opportunity to reflect on their practice and identify changes they would like to undertake. The learnings and raising of awareness included the recognition of a need for a better transition structure, information, preparation, and coordination; the existence of barriers and challenges in transition; the psychological and emotional aspects during transition; and a request for the proposed (and existing) resources and tools. These are all significant take aways addressing ongoing issues in transition care.[3,4] However, intents of action are not yet action and it will be the task of the institutional transition program to leverage on this effort to raise awareness and pursue action.

Local Team-by-Team Engagement to Support Institutional Development

In an age of increasing digitalization and automation in healthcare settings,[40] the strategy of touring clinical teams and meeting them in person could appear archaic. Yet, this effort was appreciated and created momentum which would be hard to

imagine without this engagement. Virtual and online training is reported as effective for the update of medical knowledge,[41] but in large institutions, breaking the barrier of anonymity of clinical program leaders, building trust, and developing relationships remain important – beyond the integration of new knowledge – to foster organizational change. Moreover, as one of our underlying goals was to break silos between clinical programs, we had to undertake a process of knowledge sharing that also recognized how certain clinical programs were already active in tackling transition and engage in creating bridges with the institutional transition program and with other departments. On this note, participants reported suggestions for structural changes and policy improvements; propositions for interdisciplinary collaboration and knowledge sharing; improving the transition experience for young adults; and a request for awareness and communication tools. These outcomes correspond to the initial desire to inform and raise awareness about transition but to also encourage action and collaboration. Accordingly, our grassroot, door-to-door, process yielded desirable outcomes.

Relevance of Deliberative Wisdom Theory

Finally, the study proved to be a telling example of how healthcare professionals can be motivated to adopt a gaze that moves beyond the search for mere ethical acceptability and ethical compliance to engage with deeper ethical considerations related to the flourishing of youths with chronic illnesses.[27] This motivation – in line with deliberative wisdom theory – proved to be an ongoing strength of the broader project of which this interactive workshop-based study is part.[11,31] This focus on human flourishing also served as a motivation to examine critically current transition care programs and then to imagine better care and generate ideas for improvements. For example, in our results, healthcare professionals recognized how ongoing barriers faced by youths undermine their ability to thrive in adult life and reach their potential. They also proposed policies and clinical practices to address these multifaceted issues such that youths would be made more autonomous and empowered to orient themselves in the transition. These results as well as other recent studies informed by deliberative wisdom theory – support the idea that participatory and co-creative ethics research and ethics interventions can be powerful levers of change [42-45] given their ability to tap into values and intrinsic motivations[46] and to stir creative thinking.[47]

This study bears limitations such as having been documented in a limited number of clinics in a specific pediatric setting. Given that some of the team members are active clinicians in the setting, there could be social desirability bias. Likewise, roughly half of participants completed the online survey, introducing the possibility that there is a discrepancy between responders and non-responders although the results show high levels of appreciation with limited but not impossible sharp differences between responders and non-responders to the survey. However, since the 10 workshops were organized independently, it would be surprising that 10 teams would reproduce the same biases.

Conclusion

Transition is a crucial period in the care of youths with chronic illnesses. Awareness and action toward improvement of transition care are still in need of progress. Importantly, ethical aspects of transition care are under recognized but are crucial to its alignment with the values and aspirations of youths. Face-to-face, in person interactive workshop-based awareness raising is a promising strategy despite its apparent outdated style. Embedded in an ongoing participatory study on transition, this process proved successful notably in raising awareness, sharing information, generating learnings, and supporting reflection on further action and practice changes in a spirit of co-learning. These are all significant steps toward tailoring healthcare to the personal needs and aspirations of youths with chronic illnesses. We hope this momentum will pave the way for broader and stronger institutional support and mobilization toward institutional developments of transition care and broadening the gaze of ethics – in line with deliberative wisdom theory – toward human flourishing.

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Moral Distress in Healthcare Organizations: Detection, Mitigation, and Prevention

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ABSTRACT: The nature of healthcare work often places professionals in ethically complex, high-stress situations that can lead to moral distress – an experience that not only harms individuals but also undermines job performance and organizational effectiveness. To preserve mission integrity and retain a resilient workforce, healthcare leaders must ensure staff can perform their duties without undue emotional or ethical burdens. This requires proactive organizational support and investment in ethics infrastructure. This paper explores strategies healthcare organizations can adopt to address moral distress on several levels: (1) detecting its presence within the workforce, (2) mitigating its impact when it arises, (3) preventing its recurrence by addressing systemic root causes, and (4) continuously learning and improving through structured evaluation and action. We introduce a Moral Distress Mitigation Assessment to help leaders evaluate the extent to which their institutions have the capacity to support ethical practice and employee well-being. In addition, we propose specific, actionable metrics to track progress over time. By integrating ethical awareness into leadership practices, resource allocation, and quality improvement systems, organizations can reduce moral harm while enhancing staff engagement, patient care, and operational sustainability. Values such as compassion, respect, and care must be reflected not only in patient interactions but also in the internal culture that supports those delivering care. Leaders have a moral obligation to foster environments where staff are supported with the resources, structures, and guidance they need to navigate ethical challenges without undue emotional or psychological harm.

KEYWORDS: Moral Distress, Moral Injury, Moral Residue, Organizational Ethics, Quality Improvement, Resource Allocation, Wellbeing

Definitions

The terms *moral distress, moral injury* and *moral residue* all focus on different aspects of the moral and psychological effects of ethical dilemmas. While there are many explanations for these terms, the following definitions are commonly used by the authors:

Moral distress occurs when an individual knows the ethically right thing to do but is unable to act on it due to external constraints (e.g., institutional rules, legal barriers, or organizational pressure), leading to feelings of frustration, guilt, or powerlessness.[1] Moral distress can lead to burnout, job dissatisfaction, and a decrease in quality of care.[2]

Moral injury refers to the psychological, emotional, and spiritual distress that arises when an individual perpetrates, witnesses, or fails to prevent events that deeply transgress their moral beliefs and values. It is often used when individuals face traumatic, morally distressing experiences. The long-term psychological and social effects of moral injury can include post-traumatic stress disorder.[3]

Moral residue refers to the lingering feelings of guilt, regret, or unresolved moral conflict that remain after an individual has acted in a way that conflicts with their moral beliefs or values. Unlike moral distress, which occurs at the time of the moral conflict, moral residue accumulates over time and can have lasting psychological consequences.[4,5]

Introduction

In the last several years, a rising concern for leaders of health care organizations has been the uptick in professionals and staff who report significant degrees of moral distress associated with their jobs and work environment. This phenomenon affects physicians, nurses, allied health, and support personnel alike. (See "Definitions" box for definitions of moral distress and related terms.)

Though the etiology of moral distress may vary for the different groups, the result is the same. Disengagement, burnout, resignation, early retirement, depression, and leaving health care all together have been reported as outcomes of unmitigated moral distress.[6,7] With the current and projected shortages of health care professionals and staff, it is a strategic imperative for health care organizations to retain the personnel they have and not lose people to the impacts of unrecognized or unaddressed moral distress.

This article provides an overview of moral distress in health care organizations, its causes, effects, and offers strategies that leaders can employ to detect, mitigate, and ideally prevent moral distress from taking hold in an organization.

Causes and Effects of Moral Distress in Healthcare

Moral distress arises when people are prevented from acting in accordance with their ethical beliefs, a situation that is all too common in complex clinical environments. Sometimes, individuals clearly recognize the right course of action but are constrained by institutional policies, legal limitations, or hierarchical decision-making struc-

tures. At other times, they face ambiguous or novel situations and lack the time, support, or resources to thoughtfully determine what the ethically appropriate action should be. In either case, the result can be a profound internal conflict that leads to feelings of powerlessness and frustration. This disconnect between professional values and real-world constraints is at the heart of moral distress, and over time, it can negatively impact individuals and organizations.

The prevalence of moral distress in healthcare is alarming. Up to 61% of nurses regularly experience moderate to severe levels of moral distress in situations where they cannot act according to their ethical beliefs due to constraints such as institutional policies or medical orders.[9,10] And between 40-60% of physicians report experiencing moral distress, particularly in cases where they feel they cannot provide optimal care due to system constraints such as resource limitations or administrative policies.[11] A 2023 cross-sectional study indicated that approximately one-third of academic physicians reported an intention to leave the current institution within two years.[12]

There are many potential causes of moral distress in a healthcare setting. The inability of individuals to act in accord with the organization's stated mission and values is often a driver.[13,14] Other factors include organizational policies that prevent people from following what they believe to be the best course of action for a given situation, and resource limitations such as staffing shortages, time constraints, or financial limitations, all of which can prevent people from providing the level of care they believe is necessary.[11]

Difficult clinical situations are common causes of moral distress. Healthcare professionals often report distress when patient family members demand treatments that the respective clinician believes are not in the patient's best interest.[6,15] For example, providers who care for dying patients (or patients who are at the end of their life) may perceive that a patient is suffering unnecessarily with life-sustaining treatment but are unable to facilitate a different approach such as withdrawing life support. These types of conflicts are often rooted in strongly held cultural or religious beliefs.[16]

Individual factors can also be drivers of moral distress. For example, less experienced professionals and those who have not received sufficient training in ethical decision-making may be less able to resolve moral conflict, and as a result be more susceptible to distress.[17]

The effects of moral distress in the workplace have significant business and operational implications that extend beyond the well-being of individual workers and can adversely impact organizational culture, performance, and the financial bottom line. Providers may be less able to engage with patients effectively or provide optimal care, which can lead to lower quality of care, reduced patient satisfaction, and more medical errors.[6] And moral distress has been shown to contribute to burnout, emotional exhaustion, and disengagement, resulting in higher turnover rates that are costly in terms of direct recruitment costs and indirect costs related to reduced productivity, loss of institutional knowledge, and impact on team morale.[18]

When organizations fail to address moral distress, trust between employees and management can also erode. Staff may feel that leaders are not concerned with their well-being or do not take ethical concerns seriously, leading to a loss of trust in the organization.[19] Leaders play an especially key role in addressing the issues that make workers feel isolated in their ethical struggles, or unable to voice their concerns.

Finally, moral distress can lead to higher operational costs. Nelson et al. provide a framework for understanding the potential cost implications of ethical conflicts and resulting moral distress on organizational performance, including variables such as staff efficiency, wages, turnover, and loss of business. The authors suggest that the use of ethics resources is essential to address ethics conflicts in the clinical setting, including their impact on the healthcare organizations margin.[20]

Detecting Moral Distress in The Organization

The literature consistently notes that the key to addressing moral distress is to recognize how an organization's ethical conflicts, decisions and practices are contributing to the issues that result in distress. Mitigation begins by avoiding blind leadership, which we define as the lack of recognizing the presence, scope, and implications of moral distress. A blind leader is one who does not recognize or understand the complexities or consequences of ethical challenges in their organization, and as a result, is incapable of fulfilling their ethical responsibility to staff. Due to a lack of understanding of what is occurring, healthcare executives can miss the obvious presence of ethical challenges within an organization, including the resulting moral distress. The situation can manifest itself when the leader has either flawed or incomplete information, which can create blind spots in

Effects on Organizational Performance by Cost Categories*

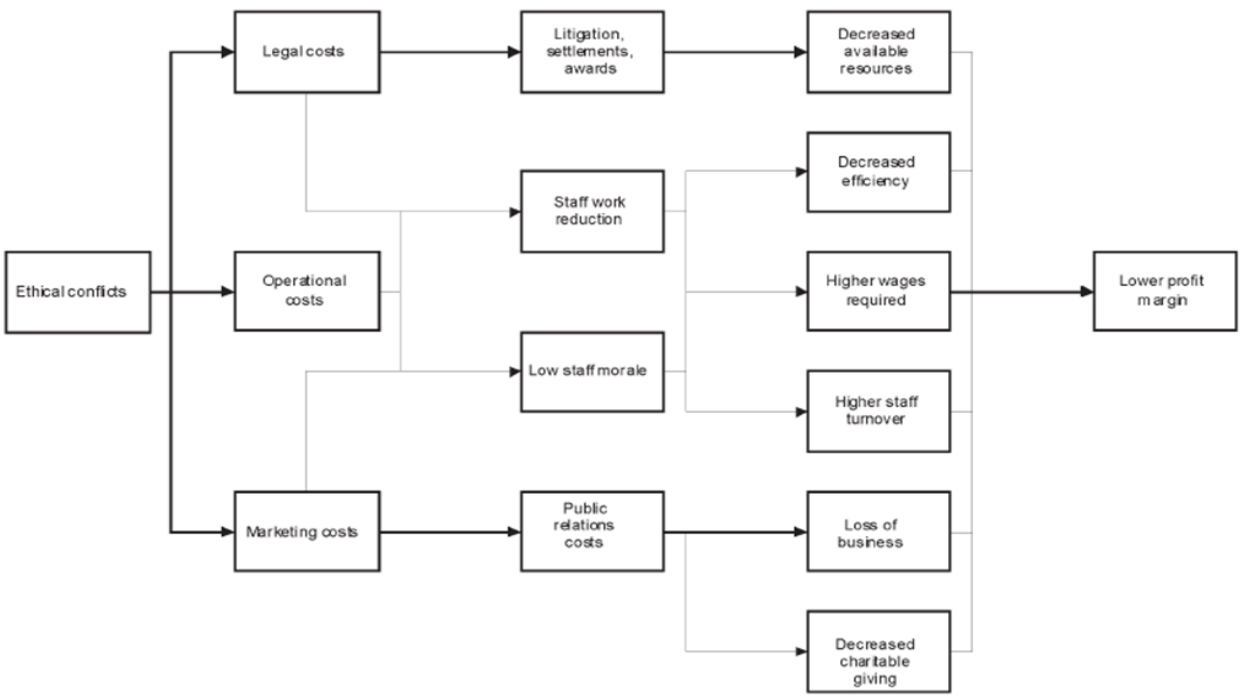

***Diagram Credit:** Nelson WA, Weeks WB, Campfield JM. The organizational costs of ethical conflicts. *J Healthc Manag.* 2008;53(1):41-52. https://journals.lww.com/jhmonline/pages/default.aspx

recognizing the presence of moral distress within one's organization. The result of such blindness can affect decision making or, in some situations, result in the lack of needed action. Removing blinders requires that leaders possess accurate information and insight. Lack of clear, accurate information can create a false understanding that all is fine.[21] It is also important to note that blind leadership is different than having accurate information and choosing to not act on it, which is why it is incumbent upon boards of trustees to insist upon transparent metrics.

Leaders have a variety of options available to assess for moral distress in their organizations. Some of these options are direct approaches, and others are indirect approaches that require more exploration to definitively detect and diagnose moral distress (e.g., turnover is a metric that may or may not signal moral distress in a work unit and should be investigated with that question in mind).

Direct methods can include information gleaned in a typical morning huddles, debriefings, or weekly meetings in which highly distressing events are shared with the leadership team. Such reports might come from the front line of the organization via management reporting lines, from a house supervisor report, or a daily safety huddle. As leaders hear about these events, they should be on the lookout for reports of situations that can be expected to cause moral distress for the staff. Such reports also point to a reasonable target for the follow-up leader rounding to make an up-close-and-personal assessment of a respective care team's functioning.

There is an array of available survey instruments that organizations can deploy to measure engagement, staff satisfaction, ethics climate, and safety culture. Items on these surveys may seek to measure either directly or indirectly the presence of moral distress in the organization. For example, in staff engagement surveys, a typical question asks: "Do you believe that senior management behaves ethically?" In safety culture surveys, the participants are queried about psychological safety in reporting safety concerns. Clearly, "low" scoring in these items is a direct warning signal that moral distress could be present. Indirect measures such as a decrease in organizational engagement or a decrease in perceptions of a safety culture could possibly implicate moral distress as a root cause. It these cases with multiple potential etiologies, is important to actively rule out moral distress rather than assume it is not a factor.

Other indirect indicators of moral distress in a

work team or in a department include the rate of staff turnover, or how staff are indicating "intent to leave" on engagement/satisfaction surveys. People will often choose to leave a work area that is causing moral distress to mitigate the ongoing impact rather than to continue to work in a setting that compounds the level of distress. Again, turnover and intent to leave have many causes, so a detailed and careful assessment is required to identify root causes of each phenomena.

Additional indirect signals for detecting moral distress in the organization can be gleaned from a periodic review of the Ethics Consultation Team's activations. Is the team activated routinely from a certain area or department of the organization? Do the types of activations have common features? Are there members of certain disciplines (e.g., nurses, trainees, assistive personnel, etc.) who are activating the Ethics Consultation Team at rates higher than others or more often than the norm? The analysis of such data may indeed point to areas in the organization that need further exploration to understand if moral distress is present and growing among the staff.

Perhaps the most subjective indicator of moral distress is the nature of the work and how it elevates the risk of moral distress. Moral distress related to ethical conflicts, such as participating in care when decisions run counter to one's own personal values, can be prevalent in specialty areas such as critical care, emergency services, maternal/child health, psychiatry, hospice and areas that care for individuals who suffer a high burden of chronic illness. Moral uncertainty is likely a hallmark of caring for patients and families in these specialty areas. Simply an awareness that these areas are at higher risk may call for surveillance of team members that is more routine than episodic. In addition, these areas may call for specialized orientation and ongoing support and training to build knowledge, skills and attitudes for the management and mitigation of moral uncertainty to prevent its progression to moral distress.

To help leaders proactively identify and address organizational contributors to moral distress and to build capacity to address the root causes, we propose a Moral Distress Mitigation Assessment. Unlike traditional approaches that rely primarily on ethics consultation services or committees, this tool enables leaders to evaluate the structures, processes, and culture that shape ethical decision-making and workforce well-being. Functioning like an internal audit, the Assessment prompts the user to reflect on whether ethical principles are truly embedded in an organization's values, operational practices, and performance measures. By establishing a clear baseline, leaders can more effectively identify gaps, strengthen infrastructure, and create conditions that support employees in delivering care consistent with their professional and moral commitments.

Moral Distress Mitigation Assessment [22]

Assessment Item	Indicators / Measures	Examples of Data Sources
Does the organization make a firm commitment to ethical decisions and actions via its mission, vision, or core values?	• Explicit mention of ethics/integrity values (fairness, stewardship, autonomy, compassion, respect) in formal statements • % of staff who can recall organizational values • Frequency of values references in executive/board decision-making	Mission/vision documents; staff engagement surveys; board/leadership meeting minutes; policy documents
Does the organization's scorecard of critical measures reflect its stated ethical commitments?	• Presence of equity- or ethics-related metrics on organizational dashboards (e.g., readmission disparities, patients' ethics experiences) • % of leadership reviews that include ethics metrics • Evidence that scorecard data is linked to QI actions • # of ethics policy violations	Organizational dashboard/ scorecard; quality reports; leadership review documents

Do all staff have access to ethics resources that resolve systemic issues?	• % of staff reporting awareness/ accessibility of ethics resources • Existence of clinical & organizational ethics committees • Frequency of staff use of ethics consults • # of clinical and/or organization ethics challenges	Committee records; ethics consult logs; staff training records; annual staff survey
Are quality improvement efforts linked to ethics committee functions?	• % of ethics consults resulting in QI recommendations • Evidence of tracked outcomes for ethics-related QI projects • Documentation of feedback loop from ethics committee to QI team	Ethics committee reports; QI dashboards; tracked outcomes data
Do clinician compensation models incentivize quality of care? Are clinicians involved in designing them?	• Proportion of variable compensation tied to patient outcomes/quality • Evidence of clinician involvement in compensation design • Staff perception of fairness in pay (survey)	Compensation policy; HR records; physician survey data
Are there clear care pathways for common clinical situations that have high potential to fuel clinician moral distress?	• # of clinical situations with documented care pathways • Existence of review/update process • Adherence rates to agreed pathways	Specialty committee reports; clinical guidelines; EHR adherence data
Do clinicians feel able to have honest, values-based conversations with patients about care options?	• Use of shared decision-making aids for top interventions • % of clinicians trained in SDM • % of patients reporting involvement in care decisions • Trust scores on patient experience surveys	Shared decision-making toolkits; training logs; patient satisfaction/ CAHPS surveys; referral outcome reports
Does the organization allocate care management resources to those most in need?	• Risk stratification models in use • % of care management resources allocated by patient need/complexity • Staff perceptions of fairness in resource allocation	Population health dashboards; care management logs; staff/patient surveys
Does the organization actively promote use of ethics resources for conflicts?	• % of leaders mentioning ethics resources in communications • Frequency of organizational reminders about ethics support • Utilization rate of ethics consults/ resources • % of staff reporting awareness of how to access resources	Internal communications; consult logs; staff engagement surveys; training participation data

Is moral distress measured, monitored, and addressed?	• Annual administration of a validated moral distress scale (e.g., MDS-R) • % of units reporting moderate/high moral distress • Action plans developed based on results • Staff turnover rates linked to moral distress findings	Moral Distress Scale results; HR exit interviews; unit-level QI reports

Scoring
For each item in the table, assign a score of 0,1, or 2 based on the evidence collected.

Score	Definition	Example
0 = Absent	No evidence the standard is in place; values or processes not articulated or not measured.	No mention of ethics in mission/vision statements; no ethics resources available.
1 = Partial / Emerging	Evidence exists but is inconsistent, incomplete, or not systematically measured; limited staff awareness or engagement.	Ethics language present in mission statement but not operationalized in scorecards or training.
2 = Established / Integrated	Strong, consistent evidence the standard is embedded in structures, processes, and outcomes; routinely measured and acted upon.	Ethics commitments in mission/vision statements are reinforced through scorecards, staff training, and leadership communications; metrics tracked over time.

Interpreting the Total Score
- 0–7 = Low Capacity: Ethics not well-integrated; moral distress likely unmanaged.
- 8–14 = Developing Capacity: Ethics commitments present but inconsistently applied.
- 15–20 = Strong Capacity: Ethics embedded in structures; measurable progress.

Mitigating Moral Distress in The Organization

There is no one model of intervention to address moral distress. Some healthcare institutions have implemented support groups to assist providers in coping with moral distress at the individual level. At other institutions, ethics committees have been instrumental in addressing moral distress. For example, for an ethics consultation, the consultants will meet with the staff involved to discuss the stress related to ethics conflicts. Additionally, while discussing moral distress with the parties involved, it may become clear that systemic institutional change is required to mitigate avoidable situations of moral injury and burnout.[23,24]

Institutions can adapt or modify various interventions to fit organizations and provider groups of different sizes, recognizing that both the intensity of moral distress and the resources available to address it can vary widely.[7] More research is needed to determine which strategies are most effective across diverse contexts and whether some approaches are better suited to addressing the immediate versus long-term consequences of moral distress, moral residue, moral injury, or burnout.

In the meantime, regardless of the specific strategy used, organizations can take meaningful steps now to strengthen their ethical infrastructure and support systems. Building and sustaining effective mitigation resources requires proactively addressing potential ethics conflicts as part of ongoing operations, which goes beyond responding only to acute clinical cases. This broader, systems-level approach calls on chief administrators and clinical leaders to examine their decisions and actions through an organizational ethics lens that aligns with the institution's mission and values. As Rorty reminds us, leaders "walking the talk" are essential to the ethical integrity and overall success of their organizations: [25]

I. Decisions made by individuals in the organization have ethical implications for organizational morale, reputation, and viability.
II. Decisions made and actions taken on the organizational level have ethical implications for individuals in the organization.
III. The operation of the organization has ethical implications for the social environment within which it operates.

Organizational leaders have a moral obligation to create environments where staff are supported with the resources, structures, and guidance needed to navigate ethical challenges that could result in distress. This obligation includes protecting employees from undue emotional or psychological harm and ensuring that ethical decision-making is treated as a core dimension of organizational health rather than an afterthought.

Preventing Moral Distress

Given the downstream impacts of moral distress in an organization, efforts aimed at preventing or decreasing ethical conflicts are a good investment for leaders and their institutions. Organizations should establish robust systems for addressing ethical conflicts, such as the ethics committees' consultations services. Organizations should support ethics committees to seek avenues to prevent conflicts from occurring. When organizations integrate a preventive ethics approach – such as ethics training, peer support, mentoring programs, and ethics focused policies – moral distress can be minimized or avoided, leading to healthier employees and more effective organizational performance.[26,27]

To facilitate a preventive approach, we suggest applying a Learning Health System (LHS) approach which the Agency for Healthcare Research and Quality describes as a "health system in which internal data and experience are systematically integrated with external evidence, and that knowledge is put into practice. As a result, patients get higher quality, safer, more efficient care, and healthcare delivery organizations are better places to work."[28] Healthcare organizations across the country have implemented the LHS approach which is endorsed by the National Academy of Medicine and the National Institutes of Health.[29]

The area of ethical conflicts has received little attention in the development and implementation of LHS activities in today's healthcare institutions. Yet, we believe ethical conflicts are a topic ripe for focus. A few published models for performing an ethical decision-making process have included a decisive step focusing on what can be done in the future to prevent the same type of conflict. Despite this important approach to ethics conflicts, few institutional ethics programs or committees have systematically implemented an improvement approach.

Many ethical conflicts are addressed and resolved through in-the-moment provision of ethics consultation However, as noted earlier, frequent recurring ethical conflicts also impact the institution's margin. Applying a learning healthcare systems approach to the work of ethics committees by using improvement methodologies has real potential to decrease the presence of ethical conflicts. For example, at the very least, following every ethics consultation, there should be a debrief focusing on two questions: Why did the ethical conflict occur? And, what can we do as a system of care to decrease the same ethics conflict from recurring in the future?

Implementing a LHS approach regarding ethical conflicts means that data related to ethical conflicts is routinely collected, categorized, and analyzed. In addition to the two debrief questions posed above, additional data could include the type and location of the conflict, as well as the contextual elements contributing to the conflict. These data would then be continuously aggregated and analyzed. The collection of such information related to ethical conflicts would be incorporated into an improvement process to anticipate or potentially prevent the issue from becoming a conflict requiring an intervention.[30]

Measuring and Evaluating Progress

Most leaders who have a grounding in quality improvement understand that "you can't improve something you can't measure." Accordingly, if a leader wants to know if moral distress is increasing or decreasing in their organization, they need a set of metrics that allow such measurement and analysis over time. Such high-level quantitative measures for assessing moral distress might include those mentioned earlier:

- Engagement surveys.
- Patient safety culture surveys.
- Turnover and intend to leave the organization rates.

Important qualitative metrics can be elicited through culture assessments, surveys and focus groups, such as asking the following questions:

- Do staff believe they are working in a culture of transparency and trust?
- Do staff trust that leaders are listening, concerned and capable?
- Is burnout a significant issue in the work unit?

In addition, Lahey and Nelson describe the use of an organizational ethics "dashboard" that incorporates both quantitative and qualitative measures.[14] Examples of measures that may point to moral distress in the organization include:

- The number of inpatients and outpatients completing advanced directives.
- End-of -life metrics, such as failure to follow DNR orders, disrespecting patient's directives.
- The number of ethics related policy violations, such as failure to address a medical error.
- Staff and patient assessment of ethical culture.
- The number and types of. clinical and organizational ethics consults completed annually.

Conclusions

We ignore the rising incidence of moral distress and moral injury in our health care workplaces at our peril. Organizations, especially in the healthcare sector, are driven by mission statements that often include values such as compassion, respect, and care. These values are not only extended toward the individuals they serve but should also be embedded within the organizational culture and extend to those working within the organization. The moral responsibility is twofold: organizations should create an environment that promotes the well-being and safety of both patients and staff.

Finally, if an organization expects employees to perform in alignment with its values and mission, it should ensure that they are able to do so without undue emotional or ethical distress. Employees who are morally distressed may struggle to fulfill their roles effectively, which can negatively affect patient care, quality of service, and organizational productivity. Therefore, the moral duty extends to ensuring that staff have the necessary support and resources to carry out their roles ethically and without harm to their emotional or psychological health.

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Ethical Considerations Regarding the Limits of Disclosure and Surrogate Decision-Maker Access to the Medical Information of Temporarily Incapacitated Patients

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ABSTRACT: Informed consent promotes patient autonomy by providing patients or their surrogates with the information needed to make medical decisions that align with their values and preferences. Care teams must determine how much and what type of information to disclose to facilitate informed decision-making. Surrogates who request additional information or access to patients' medical records may pose a challenge for care teams, who must balance protecting their patients' privacy with facilitating informed decision-making on their behalf. Teams may also wonder about their obligations under the Cures Act and HIPAA. We recommend that care teams disclose only the minimum information necessary for decision-making while compassionately engaging with surrogates. Specifically, empathetic listening can uncover the motivations behind surrogates' requests, enabling more informed responses and fostering trust.

KEYWORDS: Disclosure, Decision-making, Surrogates, Confidentiality, Information Sharing

Case Presentation

A 24-year-old man is brought to the Emergency Department by a housemate after he became unresponsive at home. The patient is encephalopathic and unable to provide any information to the care team. He is found to be severely hyperglycemic and in diabetic ketoacidosis (DKA). The care team immediately administers glucagon and begins IV fluids before transferring him to the ICU for further management. He remains weak and disoriented but neuroimaging shows no insults, and the team expects him to recover fully within 24-72 hours.

His housemate explains to the admitting team that they are both graduate students and were celebrating the patient's birthday. The housemate reports that the patient is diabetic and rarely consumes alcohol but had several alcoholic drinks during the party. The following day, the patient reported feeling nauseated and dizzy before becoming unresponsive. The housemate also shares that the patient had a similar experience a few years ago when he was studying for exams and forgot to eat. Still, he is usually very conscientious about managing his condition.

The patient has not completed an advance directive and hospital social work identifies his mother as his next of kin. The patient's mother lives out of state and the care team calls her regularly to provide clinical updates. However, the patient's mother frequently asks the care team for additional information about the patient and repeatedly requests access to the patient's electronic medical record. The patient's mother shares with the care team that the patient was diagnosed with Type I diabetes at age eight, and she helped him manage his disease throughout his childhood and adolescence. The patient's mother indicates that she and the patient have not spoken in several years due to a dispute regarding his health and lifestyle. She claims that the patient was uneasy about how involved she was in his care and social life and moved out to pursue a more independent lifestyle. However, she is eager to serve as the patient's surrogate decision-maker.

The patient's bedside nurse is concerned that the patient has historically limited the information shared with his mother regarding his condition and is unsure if the patient would be willing to have his medical information disclosed to his mother now. Moreover, the patient's mother does not have access to his EMR through the user portal, which requires authorization from the patient, and the team is unsure whether it indicates an expressed preference by the patient. The nurse is concerned that the request for access to the patient's medical record is motivated by his mother's suspicion that the patient has not managed his diabetes effectively. However, she also knows that the patient might be at risk for future medical issues if he suffers another DKA event. She informs the patient's mother that, due to HIPAA, she cannot grant access to the patient's record. The patient's mother becomes angry and asks how the medical team expects her to make sound medical decisions for him without more information. The care team wants to respect the patient's privacy but also does not want to limit his mother's ability to make informed decisions by withholding relevant medical information. They decide to consult their Ethics Consultation Service for guidance.

Clinical Ethics Issue and Recommendations

Ethics Question: How should care teams balance protecting patients' sensitive information, both in disclosure and access to electronic medical information, with their obligation to provide adequate information to surrogates as part of the informed decision-making process?

Recommendations: In the case described above, it is ethically supportable for the care team to limit the information shared regarding the patient's current medical condition to those relevant to imminent, informed decision-making. While care teams should engage with the patient's mother compassionately, her role as a surrogate does not automatically entitle her to full access to his medical history and/or records. Furthermore, once the patient can communicate with the care team, it is recommended that the team speak with him directly to ascertain his preferences regarding care, access to medical records, and surrogate decision-maker(s).

Analysis

Informed consent promotes patient autonomy by providing patients or their surrogates with the information needed to make medical decisions that align with their relevant values and beliefs. Informed consent requires five interrelated elements: 1) Capacity, 2) Disclosure, 3) Understanding, 4) Voluntariness, and 5) Consent.[1] Through transparency and effective communication, healthcare providers ensure that these criteria are adequately met with their patients, thereby establishing a therapeutic relationship conducive to shared decision-making and fulfilling their fiduciary duties as medical professionals.[2]

Ideally, healthcare professionals provide patients and surrogates with relevant clinical information and clinically appropriate or recommended options from which the latter then choose. A patient's ability to choose the option which best aligns with their values and preferences is only possible through adequate disclosure of the anticipated clinical prognosis, a robust explanation of the possible interventions and/or therapeutic options, and an assessment of whether the patient's goals and values align with the stated information.

When a patient is unable to make medical decisions for themselves and decision-making shifts to a surrogate, the information provided should ensure the surrogate can act in a manner that promotes the patient's best interests and/or known values. However, two central elements of the informed consent process—how much (quantity) and what type of information (content) to disclose in order to meet the informed consent standard—become more complicated with surrogates because of the competing obligation to protect the patient's privacy. Additionally, care teams may be faced with requests from surrogates for information about the patient or access to their medical records. There are several key considerations teams should consider when determining how to respond appropriately to these requests.

Surrogate Motivations for Requesting Information

Surrogates are often asked to provide insight into the pathways of care a patient would choose and to consent to specific interventions. In these instances, it is neither unlikely nor unreasonable for them to ask questions or request additional information. Moreover, preferences regarding information sharing and decision-making reflect myriad personal and cultural variations, and these frequently manifest during interactions between care teams and decision-makers. Understanding why surrogates are asking care teams for information can help determine ethically supportable options and give insight into the approaches or framing that might best facilitate communication and trust with them. Engaging meaningfully with surrogates by understanding and supporting them can also help ensure that they act in a manner that promotes the patient's best interests and known values.

Surrogate requests for information may be expressions of concern and emotional processing: "What happened to my loved one that caused them to be in the hospital?" or attempts to intervene in a beneficent way: "I want information so I can help make them better." Occasionally, requests for access or additional information represent mistrust of the care team. This may be especially poignant if a patient declines quickly or if the surrogate has low health literacy, is unable to be at the bedside and communicate with the care team consistently, or has had previous negative experiences with the healthcare system.[3,4] Surrogates may also believe that as part of their role as the patient's representative they have some stewardship or ownership of the patient's medical information.[5]

It is worth noting that many of these inquiries or requests are well-intentioned, and care teams should respond in turn with compassion. Empathetic and active listening combined with education may help resolve some of these concerns.[4] Where it does not, healthcare providers may be concerned about revealing too much or too little

information, especially if the patient suffers a poor outcome. They may worry that their response to the surrogate's request is unduly influenced by bias, or that if they do not initially disclose information and later must that it will further erode the trust between them and the surrogate. Furthermore, they may worry that revealing too much information to a surrogate could damage the therapeutic relationship between them and the patient if they regain the ability to participate in their medical decision-making, which is especially significant in the context of chronic or progressive diseases.[6]

Privacy and Confidentiality

Where privacy is the right of an individual, confidentiality is the obligation to honor that right.[7] Patients retain the ability to control access to themselves as part of the negative right to not be intruded upon without their consent. Healthcare professionals should weigh the benefits the information would provide to the patient against the potential harm that could result from disclosing their information, as well as any available information about their preferences regarding the disclosure of their information. Healthcare professionals must also be cognizant of the medicolegal context. The 21st Century Cures Act was signed into law in December 2016, with provisions established to bolster health information interoperability and limit "information blocking." Information blocking refers to any practice that prevents, limits, or discourages a patient from accessing their electronic health information. The Cures Act aims to enhance patients' access to their electronic health records and empower them to make informed decisions about their healthcare. Still, various practical questions associated with clinical ethics consultation methodology accompany the paradigm shift to mass and immediate access to one's medical information. Notably, the Cures Act contains an exception for preventing harm, which allows actors to engage in practices that are reasonable and necessary to avoid harm to a patient. It also does not supersede existing state or federal laws, such as HIPAA.

While a reasonable person or subjective standard may provide guidance on the amount of information that healthcare professionals should provide to patients,[1] there is an argument to be made for starting with a more conservative standard for surrogates. For surrogates, excessive information risks intruding on the patient's right to privacy without a clearly defined need and proportionate benefit to outweigh any harms of disclosure. Providers and other healthcare professionals can gauge the necessary information threshold when discussing with a patient's surrogate by asking themselves: "What is the minimum amount of information I would need to provide for them to make an informed decision about X choice?" This is not only consistent with guidance on the disclosure of health information under HIPAA, but it also serves as a strong safeguard for the patient's privacy. Care team members should be mindful that they may disclose more information, if necessary, but it is never possible to rescind information once it has been shared.

Surrogate Appointment

Surrogate decision-makers are identified in two ways: (1) by the patient's explicit designation of a healthcare agent, or (2) by operation of state law that establishes a default hierarchy when the patient lacks capacity and has not named an agent. In the state relevant to the case cited, the statutory order is: (1) healthcare power of attorney, (2) spouse, (3) legal guardian, (4) adult children, (5) parents, (6) adult siblings, (7) grandparents, (8) adult grandchildren, (9) adult niece/nephew/aunt/uncle (first degree), and (10) an adult friend. Although the exact sequence varies by jurisdiction, most states use a similar structure.

Designation of a healthcare agent does not, by itself, confer full access to the patient's medical records. Assumptions that patients intend full disclosure are unwarranted, and many institutions require explicit authorization—such as adding an approved proxy or authorized user in the electronic medical record—before granting access to medical records. Even in the absence of an explicit objection, clinicians should not assume that all medical information may be shared with a surrogate; disclosures should comply with applicable consent, privacy, and minimum-necessary standards.

However, access to medical information is crucial to enabling a surrogate to act as a representative of the patient when the patient is unable to act on their own behalf. Thus, a surrogate's entitlement to medical information must be judged by its relevant utility; it is not a blanket entitlement to the patient's past, present, and future medical records. In our patient's case, it is significant that he neither named his mother as his healthcare agent nor established her as an authorized viewer

of his record. In the absence of a patient's explicit authorization of an individual to access their record, the appropriate step is to maximize their privacy.

Prognosis and Time

In our patient's case, his prognostic outlook is favorable and he is expected to recover fully within 24 to 72 hours. Where decisions need to be made to restore his capacity or whose delay may jeopardize his life or health, it is reasonable to inform his mother and ask her to make relevant medical decisions or provide consent for ongoing therapies. For decisions that do not meet this threshold, it is more ethically defensible to delay until the patient can provide insight into his preferences for care or information sharing. When prognosis is more uncertain or recovery timelines are expected to be longer, the issues at hand are more complex. In these instances, it may be ethically justifiable to provide additional information to surrogates to facilitate informed decision-making. For example, suppose the patient suffered cerebral edema, a rare complication of DKA for adults with a significant mortality and morbidity rate. In that case, his mother may be asked to provide insight into the patient's values regarding the withdrawal of life-sustaining treatment or the suspension of further therapies. Likewise, if the patient had an underlying condition or comorbidity that made him more likely to experience recurrent DKA or would affect the benefit and risk assessment of treatment options, then it would be ethically justifiable to discuss it with his mother to provide a more comprehensive understanding of his clinical reality.

Limits of Autonomous Choice

Patients and their surrogates are empowered to exercise their right to choose from available medical options. Still, this does not imply an unfettered right to demand treatment or options that are not available or possible. The same rationale applies to confidential information. Although surrogate decision-makers require a minimum threshold of disclosure to make informed decisions regarding a patient's medical care, maintaining a confidential relationship should take precedence unless disclosure is necessary to prevent serious harm or to thwart a more significant violation of ethical principles. Moreover, providers should place greater emphasis on the patient's perceived or previously expressed values when determining the appropriate disclosure of information to third parties.

In the patient's case, the care team provided the necessary information for his mother to make decisions about his acute issues. If her reasons for requesting additional information or access are not necessary to fulfill her responsibilities as his surrogate, the care team is not obligated to provide them. However, the care team can help ensure they are supporting the patient's mother as a surrogate by reiterating their shared obligation to the patient's well-being, privacy, and dignity, as well as articulating the ways the patient's surrogate can contribute to these obligations.

Strategies for Consultation and Guiding Questions

Questions to Ask

I. Why is the surrogate asking for additional information or access? What are their driving motivations, fears, concerns, interests, beliefs, etc.?
II. Is there evidence of the patient's wishes regarding the disclosure of their information, such as previous statements or the designation of authorized users?
III. Is the information being considered for disclosure essential to the decision the surrogate is being asked to make?
IV. What is your state's or institution's policy on deferring to a surrogate decision-maker? For example, do statutory rules—such as a mandated hierarchy of surrogates—require the care team to defer medical decisions to a specific individual when the patient has not named a surrogate or cannot choose one?
V. Is it expected that the patient will regain capacity in the near future?
VI. What is the impact of disclosure or non-disclosure on the patient and their decision-makers?

Strategies

I. Healthcare professionals should familiarize themselves with their institutional policies and practices regarding access to medical records.
II. In conversations with surrogates, healthcare professionals should emphasize the importance of centering the patient and acknowledging their values in a substitutive manner

when considering the clinical information pro vided.

III. Empathetic listening may help uncover the root of surrogates' requests and open pathways to address those concerns without requiring disclosure of the patient's medical information (e.g., speaking in general about a condition or providing resources, facilitating video viewing of the patient, etc.).

IV. Encourage patients to engage in advance care planning, including designating a healthcare agent, authorizing access to medical records, and/or completing an advance directive. Ethicists and trained ACP facilitators can support patients and guide such conversations while they are in the inpatient setting.

Case Resolution and Conclusion

In our patient's case, the care team explained to his mother the importance of respecting his privacy and their desire to support her as a decision-maker. When asked for more details on her concerns about decision-making, his mother acknowledged that she worried about how well he was managing his condition but was more worried about inadvertently making a decision that would increase his risk of neurological injury. The team alleviated her concerns, and the patient returned to baseline approximately 36 hours later.

Facilitating informed decision-making by surrogate decision-makers is essential and surrogates may often request additional access or information as they try to act on a patient's behalf. Care teams should recognize this and respond compassionately but must also remember that their obligations are to the patient and their best interests. These interests include privacy and control over access to one's body, and these should be maximized where possible. Any information disclosed to surrogate decision-makers should be directly relevant and essential to their ability to make decisions in the patient's best interests, the minimum amount necessary to make an informed decision, and with a proportionate benefit to the harm of disclosing. In our case study, the patient's incapacitation prompts a delicate balance between transparency and patient confidentiality. Our recommended approach ensures that the patient's mother receives sufficient information to make informed decisions about her son's medical treatment. At the same time, it respects the patient's autonomy and fosters a compassionate and ethical response to the family's needs during a challenging time.

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