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THE JOHN J. LYNCH, MD CENTER FOR ETHICS

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ROUNDING WITH THE EDITOR

Embarking on the Next Decade

Evan G. DeRenzo, PhD

Dear Readers,

Welcome to Volume 10, No. 1; the second decade of volumes of the *Journal of Hospital Ethics* (JoHE). It's hard to believe we're here. But we are, and it's so exciting.

When we started producing JoHE, none of us appreciated what it was really going to take to run a professional journal. We were just learning to fly the plane as we were flying the plane. Today, embarking on the next decade of JoHE volumes, this momentous juncture has given us the opportunity to step back and contemplate moving forward more thoughtfully than when we began. Towards that end we are making some changes, both substantive and aesthetic.

Substantively, JoHE is evolving. When we began, we called on friends and colleagues around what was then just Washington Hospital Center (now MedStar Washington), and the wider MedStar system, calling in favors from all directions.

At the beginning, the format was quirky. We wanted JoHE to stand out in the field of clinical ethics journals. Each issue had a special topic with all features devoted to a different ethical aspect of that topic. There were most often three (3) case studies in a section headed "In Practice." Now we are a more mature journal with our format conforming to that of well-established publications.

As to peer review, this is where our own publication experience paid off. We knew enough from having published our own work that a double-blinded peer review process quickly became a cornerstone of JoHE's editorial policy.

Our processes for generating articles, however, had their own idiosyncrasies. Because we were cultivating authors from our local hospitals, we were eliciting articles from clinicians based on a superior clinical and clinical ethics reputation. That meant most submissions needed much rewriting before being ready to go out for peer review. We might work with authors for months to ready their submissions for peer review, almost assuring that we had a high acceptance rate, a rate we thought, in our incipiency, was a great goal. Now with articles steadily rolling in 'over the transom' (an old-fashioned publishing term-of-art referring to unsolicited manuscripts being thrown at publishers through the open, narrow window at the top of heavy doors), our acceptance rate is rapidly and appropriately declining.

Like always having had double-blinded peer review, JoHE is, and has always been, a center piece of the Lynch Center's educational mission. But at the beginning, JoHE was envisioned as being written with a lighter touch than a standard medical journal – perhaps more like articles in *The New Yorker*, albeit intellectually rigorous.

Today JoHE is more academic. Not only is it written for physicians, JoHE is written for those who teach hospital medical ethics, for those who engage in research about hospital medical ethics, and to the full panoply of providers involved in the hospital care of patients, families, and friends. Although we have always had an intense and exclusive focus on hospital medical ethics, the articles have grown more academic and often longer.

Which leads me to this issue's contents. This issue starts with an article by Joshua Dyachim on one of the hottest topics around, artificial intelligence (AI). Examining how AI may be used in identifying pain in nonverbal patients could be the harbinger of a real medical breakthrough. With AI having already started popping up all over in clinical care and research, applying this high-powered technology to identify pain in nonverbal patients is so exciting. These are the patients whose pain, even in excellent hospitals and nursing homes, can go unnoticed. If one isn't really looking, this particularly vulnerable group of patients may be suffering without that suffering being recognized and treated. Such is a possibility that ought to send shivers down the spines of providers, caregivers, families, and friends. If AI can be applied to improve prospects for picking up pain in nonverbal acute care hospital patients or nursing home residents, even though AI has its own problems to be ironed out, one can only respond with "Bring it on." I refer you to the related work of a clinical ethicist and clinical ethics researcher, Jada Wiggleton-Little, PhD, who was under Christian's supervision as a Visiting Scholar in the Lynch Center's program for Neuroethics and Clinical Consciousness (PNCC) before her doctorate was completed. Wiggleton-Little's present research focus is on pain communication.[1]

Also, I refer to an excellent piece of research by Schurmann and Teiter-Theil.[2] In categorizing clinical ethics problems, they found that nonverbal patients in pain are among a hospital's most vulnerable. Of course they did. Untreated pain is not only an ethics problem but a clinical ethics catastrophe.

Next is the Yu et al. paper, on their single-center study looking at clinical ethics consultations (CECs) pre- and post- COVID. Although single-center studies are often considered pilot studies, if that's the purpose of this study, that would be great. This study looked at 547 pre-COVID consults and 215 in the post-COVID period. Yu and her colleagues had hypothesized that there would be an increase in post-Covid consults about refusal of recommended medical care resulting from overall increase in public mistrust, but this was not born out. They concluded by suggesting that perceptions of increases in refusal of medical care might be related to clinician moral distress and emotional fatigue. Certainly, one might expect increased provider fatigue of all sorts post-COVID.

In general, those who were in hospitals throughout the beginning and worst parts of the pandemic were probably totally exhausted. Yet, so many CEC services went remote at the start of the pandemic that controlling for that variable in a multi-center study might be most interesting. We at the Lynch Center never went remote and worked alongside our care teams wherever they were in the hospital. That included working in our nine critical care units, wearing what felt like space suits, while patients were dying. If, for example, there were differences in post-COVID numbers returning to pre-COVID levels between CEC services that went remote and those that did not, one might speculate that such differences had something to do with how well-integrated a CEC service was in one's hospital pre-COVID. The implications of such data might point to multiple opportunities for educational activities to better embed CEC services into the fabric of a hospital, and how to garner increased levels of leadership support. Yu and colleagues' study speaks to the need for more research.

Speaking of an article that cries out for a response is the work of Yeshua on nurses being used to collect data for police. Respect for law enforcement is crucial for the flourishing of a civil society. But that does not mean that health care providers should just do what law enforcement asks without question. It seems to me that nurses, when expected to just give law enforcement what they want, ought to decline and insist on completion of proper written law enforcement forms and procedures consistent with associated hospital policies. If there is no expectation that such steps be taken just because nurses have always provided law enforcement with what is requested, that behavior ought to change. Instead, nurses should decline until such expectations are reset. That is, nurses who are asked by law enforcement for patient data, especially when obtaining such data might involve an invasive procedure to which a patient is objecting, should decline to produce such data without having gone through established procedures that protect patient care and privacy. That this standard practice has been disclosed in a medical ethics journal ought to call upon hospital clinical ethicists reading this article to explore their own hospital policies and practices to make certain that they exist and are aligned with the highest standards of care, not practices of least resistance. If changes are called for, though, it will take courage on the part of nurses who might be affected by such requests.

As I read the article, I was reminded of a project in which I worked with Norm Coleman, MD, Associate Director of the Radiation Research Program at the National Cancer Institute (NCI) of the National Institutes of Health (NIH). I had been asked to join as the clinical ethicist on a large project about emergency preparedness under conditions of a nuclear bomb attack. At first, the project sounded too outside my knowledge base for me to participate meaningfully, but I had been asked to join by a trusted colleague, Ann Knebel, RN, who was then Deputy Director for Preparedness Planning and Response, Department of Health and Human Services (HHS). Ann is now with the National Center for Advancing Translational Sciences (known as the Division of Preclinical Innovation), NIH. After months, because of Norm's support, we identified the flaw in the previously -existing clinical ethics literature's logic and corrected it in the project's resulting publication.[3]

At one of our last meetings, Norm came over to me with a beautiful rubber rooster and smacked it down in front of me. He knew it had taken courage to stand up to the open hostility of many physicians and the ethicists involved in the previously, and ethically misguided, field-defining publications, and said to me, "Never chicken out." I have kept that rubber rooster on my desk where I see it and think of Norm daily.

Nurses (and all clinical care providers) must be courageous when faced with a practice that goes on simply because it has always gone on, even though it should not. In this case, law enforcement has processes (one hopes), just like medicine has processes (one hopes), that govern how controversial practices, like this one, should be conducted. The relevant medical ethics norm that applies here is that one ought never do anything to patients – especially those who refuse to give consent – that is not in their medical best interest. So I give our readers the piece of wonderful advice Norm gave me, when faced with something one knows to be wrong, in working to fix the problem, "Never chicken out."

Next is the Frankel et al. piece, another single-center study that cries out for follow up research. But unlike the Yu et al. article, this study addresses a long-discussed topic: guardianship and decision-making for critically ill, unrepresented patients. True, this is a report of a process improvement project prompted by concerns for provider moral distress, and the inclusion of moral distress to the issues of guardianship for unrepresented, decisionally-incapacitated patients in an intensive care unit adds a new twist, but it is a new twist on an already rich literature,[4-10] including creative state legislation such as the Colorado General Assembly's HB16-1101.[11]

That this group's work resulted in assistance to clinicians in order to become more aware of ways in which these patients can obtain the guardianship protections they deserve, is an excellent outcome. What is distressing is that there was so much moral distress around guardianship for these patients. Why, with such a rich literature, are clinicians still struggling? There is no question that, on the ground, there are practical difficulties in obtaining guardians. And these difficulties might well be morally distressing to clinicians. But one wonders why these clinicians are struggling just to get on top of the existing literature.

Is the implication that clinicians have little time to research the literature? Perhaps worse, that there is so much chaos in the average critical care unit that attention to matters of guardianship slip to the bottom of the pile and so discharge is unnecessarily delayed? Or is it something more deeply structural? Could the moral distress about discharging these patients from critical care units be related to the trend over the last decade or more of turning social workers into discharge planners? Or might it go to hospitals no longer hiring credentialed social workers and replacing them with nurses? Often, because nurses are experiencing so much moral distress, they want to leave the bedside. In order to provide nurses that wish to leave the bedside a pathway to stay at their hospitals, some hospital administrators have gotten rid of their social workers all together and replaced them with those nurses. Even in the face of much research on the topic of guardianship in this population, further digging about why clinicians lack the available knowledge about guardianship might help clinicians, patients and administrators.

The last article is about a medically and psychiatrically complex patient. In this case presentation, the patient is cared for by a hospitalist who is becoming concerned that the outpatient immunologist's drug regimen may be harmful. The patient, however, has requested that the pain meds (part of her longstanding out-patient drug regimen that the outpatient immunologist consistently prescribes) be increased. The hospitalist questions whether the patient has factitious disorder. It is not clear that the outpatient immunologist even agrees there is such a condition. JoHE has already published one piece previously exploring this disorder,[12] which reflects our long-standing interest in the intersection of psychiatry and ethics. But in the heart of this article a novel concern appears: navigating the ethical obligations of the in-patient hospitalist when that hospitalist's expert treating opinion collides with the presumed expert treating opinion of a patient's physician.

These are rough waters to traverse. Clinical medicine, especially related to physicians, has long considered etiquette important to the furtherance of the profession. Physicians do not like to openly challenge or disagree with other physicians. Especially when hospitalists might have to challenge a patient's longtime treating out-patient physician, especially one that may be more academically-inclined than the hospitalist. Knowing that even if the hospitalist changes the patient's medication regimen, upon discharge the patient is likely to return to the immunologist and go back to taking the same drugs. Nonetheless, sometimes it is the hospitalist's obligation to just make the changes believed to be in the patient's best interests. Etiquette dictates also, just to make acting on the hospitalist's own instincts more difficult, that the hospitalist attempt to communicate with the immunologist to enlist the immunologist in seconding the changed treatment plan. We can only wish the hospitalist "Good luck" and that she never gives up. We hope you enjoy reading this intricately analyzed piece. It illuminates why clinical hospital ethics Is both emotionally rewarding and intellectually satisfying.

Turning now to the aesthetics of JoHE, here, too, we are evolving. Previously, JoHE's aesthetic decisions have been as quirky as its decisions about content. But now are gone the different colors with every issue. Gone is the color ribbon on the spine with a picture that has become more and more abstract and thus, unconnected and uninformative about the contents of the issue. The cover of this issue, i.e., the dove grey with "MedStar blue" lettering, is the new, forward-going JoHE cover design. JoHE's new grey background is both denotative and connotative of what lies between its covers.

Grey denotes that JoHE is a journal about matters that are often uncertain. Clinical ethicists live in the grey spaces of the hospital. Clinical ethics is not a practice of obvious answers. Whereas clinical research is a practice that involves working hard to strip a protocol down to its tightest design so as to avoid confounds at all costs, clinical medicine is messy. Grey is the best color to evoke what clinical medical ethics in hospitals is really like.

The connotation of JoHE's cover being grey suggests that the articles, cases, and reviewed books are about ethical issues in clinical hospital medicine that are nuanced and difficult to unravel. The grey harkens to the difficulties in figuring out what are going to be the best answers for patients, patients' families and friends, as well as for the hospital and community. One can always string ethics words together and throw the resulting nonsense out as some sort of answer to the question. My graduate students did it every semester's first class I can remember (if they were still doing it by the semester's end, they flunked).

But reasons count. They matter in philosophy as they do in the clinical arena. It's just that, in the clinical environment, the best answer that can be crafted is usually required about a specific patient in a specific set of circumstances, within a constrained time frame.

It would be great to hear how our readers feel about any or all of these changes. Taken together they are a lot to absorb. But we believe these changes set us up to travel well the path ahead as we continue to meet our educational mission, always seeking to do so at a consistent level of excellence. We would love to hear from you about anything that is on your mind regarding JoHE.

Before I sign off, however, we would like to congratulate Amanda Anderson, PhD, MSN, MPA, RN and Jason Lesandrini, PhD, FACHE, LPEC, HEC-C, two of the most stalwart members of our Editorial Advisory Board on completing their doctorates. Amanda is going to the US Veterans Administration, focusing on the care of, and research about, veterans experiencing homelessness. Jason continues to perform clinical ethics research and is Assistant Vice President for Ethics, Advanced Care Planning and Spiritual Health at WellStar Health System, Atlanta, GA. Knowing each of them for many years, it is a true joy for me to see these two talented, contributory individuals who I have cared about so much for so long, having met the career milestone of receiving their PhDs.

Stay safe and I hope you all find many parts of this new and evolved JoHE that you enjoy. Have a wonderful summer and be well.

Sincerely,

Evan

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Ethical Ramifications of Utilizing AI-Driven Facial Recognition Technology in Pain Assessment of Nonverbal Patients

Joshua Dyachim, DHCML, HEC-C, BCC

ABSTRACT: Accurate and appropriate pain assessment is crucial for effective pain treatment and management. When patients who are nonverbal cannot communicate, observational pain assessment carried out by health providers is riddled with issues of bias and subjectivity. Artificial intelligence-driven facial recognition technologies (FRTs) are proposed as the solution to the challenges prevalent in observational pain assessment of nonverbal patients by care providers. It promises to streamline, objectify, and promote accuracy to mitigate inaccurate pain assessment in nonverbal patients. Inaccurate pain assessment could lead to undertreatment or overtreatment of pain in nonverbal patients, with far-reaching and unintended consequences. This paper argues that close ethical scrutiny is pertinent for the deployment of AI-driven FRT for pain assessment to mitigate bias and unequal outcomes in nonverbal patients. A concerted effort by medical professionals is expedient to assure the integration of transparent, explainable, and robust data-driven FRT for pain assessment in the clinical setting to promote quality care and equitable outcomes in nonverbal patients.

KEYWORDS: Artificial Intelligence; Facial Recognition Technology; Pain; Nonverbal; Machine Learning

Introduction

Pain is one of the primary reasons people seek medical attention, and it is associated with a variety of diseases.[1] In acute pain management, pain assessment is critical for optimal pain treatment and care plan evaluation.[2] Furthermore, a valid and reliable pain assessment is required for differential diagnosis in order to administer appropriate treatment, monitor progress, and evaluate the need to maintain or alter treatment.[1] Utilizing facial recognition technology (FRT) for real-time and accurate pain assessment can assist clinicians in determining the appropriate dosage of pain medication to administer to nonverbal patients in an expedient manner, given the gaps prevalent in observational pain assessment.[2]

Nonverbal patients are a "vulnerable" group of patients who are incapable of verbal communication.[3] As used in this paper, nonverbal patients may include patients with late-stage dementia, neonates in intensive care, patients under sedation or anesthesia, individuals with intellectual disabilities, and patients at end of life.[2] Also, the term “patient” would refer narrowly to nonverbal patients in this paper. The risk of overtreatment or undertreatment of pain could have far-reaching repercussions and diminish the quality of life of nonverbal patients. This paper argues that although artificial intelligence-driven FRT promises to offer more accurate pain assessment, concerns of bias necessitate the deployment of ethically appropriate FRT to assure quality care and equitable outcomes in nonverbal patients.

Facial Expression and Facial Recognition Technology (FRT)

Facial expression is one of the most valid indicators of pain.[4] Facial expressions are regarded as the benchmark for assessing pain in nonverbal patients, as they are the most frequent and specific indicators of pain.[5] FRT is "a form of artificial intelligence in which machine learning (ML) or algorithms are applied to a data base to compare facial images in order to find patterns in facial features for verification or authentication."[6] Due to its robust capability to incorporate and learn from large collections of clinical data, artificial intelligence (AI) can drive diagnosis, therapeutic decision-making, and individualized medicine.[7] In numerous contexts, FRT is advancing by leaps and bounds and is deployed in many spaces, including healthcare.[8]

Ground Truths in Pain Assessment

Identifiers used in the development and assessment of pain recognition systems are referred to as ground truths.[9] In the literature, three fundamental principles have been identified: self-report, observational assessment, and study design.[1] Patient-reported pain assessment is considered the gold standard.[10] Since pain is a subjective experience, the best way to assess it is through self-report.[1] Common self-reporting techniques include the Visual Analog Scale (VAS), the Verbal Rating Scales (VRS) and the Numeric Rating Scale (NRS).[1] These unidimensional assessment tools have been criticized for their oversimplification, limited applicability in nonverbal patients,[2] reporting bias[10] and subjectivity, all of which have the potential to impede accurate pain assessment and diagnosis.[11]

When nonverbal patients cannot provide self-report, clinicians utilize observational pain assessment tools. Facial expression is crucial in observational analysis. Facial expression is considered a reliable and valid indicator of pain, as it is commonly included in observational measures used for pain evaluation.[4] Several observational assessment scales have been developed and validated for certain nonverbal patient populations. Some include elderly people with severe dementia, (e.g. PAINAD PACSLAC, DOLOPLUS2); infants and preverbal toddlers (e.g. FLACC, NIPS, CRIES); and critically ill and/or unconscious individuals (e.g. NVPS, BPS, CPOT).[1]

To apply observational scales reliably, a substantial amount of training and experience is required for medical professionals. Moreover, it is not feasible for clinicians to monitor patients continuously. Consequently, clinicians may miss pertinent pain episodes or identify changes in a delayed manner, potentially compromising the accuracy of pain assessment. Along with this, clinicians may be susceptible to bias and subjectivity in their evaluations due to personal factors or lack of experience.[12] Moreover, the clinician's ability to make precise distinctions at the periphery of a complex facial expression is hampered by inherent limitations.[13] Therefore, technical solutions to assist clinicians in ensuring uninterrupted pain monitoring using automated monitoring systems that employ FRT could facilitate effective pain assessment and management.[4]

Automated Pain Assessment Using Facial Recognition Technology

Owing to the limitations of observational assessment by clinicians, it is proposed that automated pain detection using FRT is the way forward. Facial pain can be measured using metrics such as the Prkachin and Solomon Pain Intensity (PSPI) score and the Facial Action Coding System (FACS). The FACS involves the categorization of facial expressions into specific units known as action units (AU). These action units serve as discrete measures of facial muscle modifications.[14] The PSPI score measures pain by combining AU intensities and detection score.[14] The PSPI score is widely utilized in pain recognition as a specialized observer scale for facial expression, mostly due to its affiliation with the widely employed UNBC-McMaster database. Additional databases such as MIntPAIN, COPE, YouTube, IIIT-S ICSD, EmoPain, SenseEmotion, and X-ITE pain databases have been employed in current FRT studies pertaining to the evaluation of pain.[1]

The FACS is widely recognized as the preferred tool for examining facial expressions in pain-related research. It has been extensively utilized in several studies exploring the manifestations of pain through facial expressions. The FACS is an anatomically-based categorization system that provides a detailed and objective analysis of facial motions. It identifies and classifies a total of 44 specific facial movements or AUs.[4] The utilization of relevance vector machine (RVM) learning techniques in pattern recognition has been a subject of recent progress, particularly in the field of pain assessment, where these approaches are employed to assist clinicians.[4] RVM continuously monitors patients and provides clinicians with measurable data for pain assessment.

Potentials of Automated Pain Assessment Using AI-Driven Facial Recognition Technology

Although health care practitioners are ethically obligated to alleviate pain, there is a prevailing belief that patients' pain is often not adequately addressed.[1] For instance, "80% of patients who undergo surgical procedures experience acute postoperative pain, and 75% of those who experience postoperative pain report its severity as moderate, severe, or extreme."[3] Current evidence indicates that there is a significant disparity in the availability and accessibility of palliative care services.[3] In addition, research reveals that the perception of pain is less readily acknowledged by clinicians when observed in individuals with black facial features compared to those with white facial features, potentially resulting in biased treatment recommendations.[15] These suggest that conventional approaches to pain assessment exhibit limited reliability as a result of the considerable inconsistency in pain scores given by patients and the subjective interpretations of pain by clinicians. To objectively assess pain, it is necessary to employ comprehensive and automated techniques for pain detection and recognition. Owing to the fact that observational assessment is plagued by ineffectiveness, subjectivity, and bias, AI-driven FRT is proposed as a panacea for enhancing accurate, timely, objective, and generalizable pain assessment, which is the foundation of appropriate pain management.

AI has emerged as a defining tool in the field of pain assessment, as it enables the automation and objectification of this process through the identification of facial expressions that are indicative of pain.[9] There is an argument that the domain where AI may have a significant impact is in the empirical diagnosis of a cardinal indicator in medicine, namely, pain.[16] The utilization of AUs as defined in the FACS facilitates the automated analysis of facial expressions, which promotes a standardized, dependable, and anatomically-grounded approach to coding facial responses.[4] Specifically, employing data-driven AI models can be leveraged to overcome the constraints associated with subjective pain assessment. AI/ML systems outperform human observers in both assessing pain intensity and detecting misleading facial expressions associated with pain.[12] Hence, "AI/ML could be a helpful tool for providing objective and accurate measurements of pain intensity, enabling clinicians to make more informed decisions regarding the diagnosis and treatment of pain."[9] Furthermore, due to the episodic nature and fluctuating intensity of pain, it is imperative to employ continuous automated pain assessment to ensure that critical pain events are not missed, especially in nonverbal patients.[2] Automatic pain assessment utilizing FRT will promote individualized, patient-centered care and assist caregivers in providing patients with timely and appropriate pain relief.

Facial image analysis plays a crucial role in facilitating the development of an automated decision system for pain assessment that would enable clinicians to devise an appropriate plan of care. It offers an objective approach of evaluating pain in individuals through the identification and analysis of facial expressions. This form of analysis reduces the observer bias of clinicians who are acclimated to perceiving conventional pain displays. Facial analysis has been incorporated into point-of-care applications such as Extracorporeal Pulse Activation Technology (EPAT) that precisely "detect facial micro-expressions indicative of pain."[14] EPAT holds benefits for nonverbal patients, especially those with advanced dementia.

The Facial Expressions Based Automatic Pain Assessment System (FEAPAS) is also an example of a system that has been designed to identify four pain categories: “no pain, low pain, moderate pain, and severe pain.”[12] Consequently, FEAPAS activates an alarm when a patient's discomfort is detected, allowing the medical team to take action. FEAPAS was designed to meet two criteria: (1) the system must be accurate enough to never overlook a valid alarm, and (2) it must be quick enough to detect pain situations and activate the alarm.[12] These technologies suggest that ML techniques for automatic pain detection are a valuable instrument for intelligent health care and precision medicine.[17]

Ethical Considerations

The emergence of ML in clinical medicine has the potential to significantly enhance the delivery of health care. Numerous AI-driven interventions are novel, and as such, their clinical validity and utility are incipient.[18] Therefore, it is necessary to proactively minimize the ethical risks associated with the implementation of AI, which can include threats to patient autonomy and informed consent, the potential for bias, and a lack of transparency.[7] Concerning the use of AI-driven FRT in pain assessment of nonverbal patients, three areas deserve particular attention: skewed data, bias and lack of transparency.

If benefits are to be realized and maximized, it is necessary to evaluate the ethical implications of ML deployment in health care. The incorporation of AI-driven FRT in the pain assessment of nonverbal patients has the potential to outperform care providers' observational assessments. Data reigns supreme in modern AI. The intelligence of AI software is limited by the data used to train it.[8] In ML, the quality of the result is proportional to the quality of the input data.[6] ML relies on a plethora of data to configure its functions.[14] Despite their potential to promote precision and accuracy in pain assessment and treatment, it is essential for care providers who utilize or rely on AI-driven FRT to be aware of their limitations and vulnerabilities based on the quality of the data used to develop its algorithm. One notable issue prevalent in the domain of AI and facial expression research is the recurring issue of sample homogeneity and the omission of essential demographic information.[19] The issue of skewed data used in developing algorithms poses a potential risk of inaccurate pain assessment that could lead to undertreatment or overtreatment among a diverse patient population, which could result in adverse events.

There is a risk of perpetuating disparities and inequitable outcomes for certain populations if researchers and AI developers do not incorporate appropriate sample demographics into the data used to develop AI algorithms.[19] Recent evidence indicates that the association between facial responses and pain stimuli varies by culture.[19] A study was conducted to analyze facial models of Western Caucasians and East Asians, which indicated notable cultural differences in the facial muscles and temporal dynamics associated with fundamental emotions.[20] The study's findings indicate that facial expressions of emotions exhibit cultural specificity rather than universal characteristics.[20] Such evidence may deflate the generalizability and applicability of AI-driven FRT in the pain assessment of nonverbal patients. The facial expression of nonverbal individuals is one of the primary presentations of discomfort. As a result, ignorance of the effect of ethnic and cultural factors on the facial expression due to pain could result in overtreatment or undertreatment of pain.[19] In addition, differences between individuals, such as facial shape, appearance, and behavior, pose an important barrier for automatic pain recognition.[1] In addition to the practical challenges posed by the curation of large data sets from interventional studies, the combination of human pain scores with facial expression data could limit the accuracy and generalizability of ML models.[10]

It is essential that the collected data be representative of the population to be served. For instance, the generalization of systems trained only on youthful faces is constrained by the textural disparities induced by skin aging, as well as the variances in facial muscle flexibility and facial motion dynamics observed in older individuals.[4] In the clinical setting, data that is biased toward a younger population compared to an elderly population that is more susceptible to pain would leave much to be desired if deployed imprudently. A "demographically balanced" criterion that guarantees equal representation of the population to be served is the veritable path forward.[21]

The potential for misdiagnosis based on flawed pain evaluation models may result in suboptimal care or medication, which may erode patients' trust in their healthcare providers.[9] There is already variation in the delivery of health care based on race.[15] Analogous racial biases may inadvertently be incorporated into algorithms deployed in health care. Conversely, it is plausible that the appropriate development and cautious deployment of ML might mitigate health inequities if the algorithms are built to account for existing biases.

The notion of objectivity in AI-driven FRT is challenged by the inherent "black box" nature of AI/ML.[14] It is tenable that ML algorithms may not provide equally accurate predictions across racial, gender, and socioeconomic groups.[7] Transparency is lacking in deep learning models. Since the developer does not explicitly program the inputs and features, it is difficult to communicate the theoretical framework behind the result of an automated pain assessment. This makes it more difficult to comprehend how they form their conclusions or assessment. In order to arrive at informed decision-making in patient care, healthcare providers must comprehend and discern the rationale underlying an algorithm's decisions.[9] The ability of clinicians to interpret AI-guided test results can assist them in identifying potential ethical dilemmas in patient care.[7] However, in the absence of explainability and transparency, the deployment of AI-driven technologies could result in the practice of "black-box" medicine.

Ethical Application of AI-driven FRT

In light of the ethical concerns raised thus far, it is crucial to explore a prudent application of AI-driven FRT in the pain assessment of nonverbal patients. Clinicians have an ethical obligation to alleviate patients' pain to the greatest extent possible, given current knowledge and resources. Patients with unrelieved pain may be extremely vulnerable. Untreated pain can compromise patients' autonomy and increase their susceptibility, while mitigated pain has the potential to safeguard patients' integrity and wellbeing.

Providers of healthcare should pursue algorithmic accountability for modern AI-driven clinical technologies such as FRT. This would promote the use of technologies and automated decisions that are more transparent, explainable and fair.[8] Such effort may put pressure on AI and ML developers to design systems and tools that can elucidate the reasoning behind generated results.[6] If this is accomplished, clinicians will be better equipped to determine the advantages and disadvantages of these technologies in patient care.[3] Even at a basic level, clinicians should strive to comprehend how AI technologies in health care are constructed, the data on which they are built, as well as their strengths and weaknesses. It is incumbent on clinicians to demand algorithmic accountability from AI developers and technology companies. The failure of clinicians involved in pain assessment to acknowledge or understand the intricacies involved in the development of ML systems, or the acceptance of their creation as black boxes, may give rise to patient outcomes that are ethically problematic.

To mitigate inequity, neglect, and marginalization in AI-driven FRT pain assessment, it is essential for clinicians to comprehend the quality and quantity of data used in algorithm development. These data must be diverse, and representative of the population being served. The data should be based on objective truth rather than just perceptions of truth.[22] There is a need to include samples that are diverse in terms of age, ethnicity, and culture when constructing an AI algorithm.[19] It has been suggested that the acquisition of data should be guided by "variety, velocity, volume, veracity, and value."[23] This would result in well-structured data and necessitate continuous updating, as AI's performance relies on it, if it is to live up to its claims of objectivity, precision, and generalizability in pain assessment.

The enhancement of quality care can be achieved by advancing an ethical framework for pain assessment. The deployment of ethical FRT can lead to accurate pain assessment, thereby enhancing effective pain management to alleviate the suffering and indignity caused by pain, a fundamental human condition. A framework based on the ethics of care would provide a connection between the epistemic domains of pain assessment and their anthropological roots, to assure their ethical appropriateness.[3] Such a framework will enable clinicians to provide patients with an informed plan of care that ensures quality care and a desirable outcome. In addition, it will reaffirm that the integration of AI technology and tools in health care is intended to be complementary and not a substitute for clinicians' role and agency in the patient-clinician relationship.

In addition, professional organizations and advocacy groups such as the American Academy of Pain Medicine (AAPM), the American Chronic Pain Association (ACPA), the Chronic Pain Research Alliance, and the U.S. Pain Foundation should keep track of new AI-driven technologies deployed in the health space and develop normative guidelines. Such guidelines can assist hospitals, institutions and clinicians in determining ethically appropriate FRTs to be deployed in the pain assessment of nonverbal patients. It is germane for AI systems to reflect high ethical standards that have served as guiding frameworks for other drivers in healthcare.[24] High benchmarks and robust internal mechanisms should be instituted to assess any AI-driven technology that will be deployed in the clinical setting.

Conclusion

This paper has emphasized that clinicians have an ethical obligation to alleviate patients' pain. Due to the limitations of self-report and observational assessment models for the pain assessment of nonverbal patients, AI-driven FRT is proposed as a potential alternative. The deployment of AI-driven FRT in the pain assessment of nonverbal patients has demonstrated its ability to outperform care providers' observational assessments. AI-driven FRT in pain assessment holds the promise of advancing reliable pain assessment methods based on generalizable, objective and standardized indicators that will assure quality care for patients and mitigate the adverse implications of undertreatment and overtreatment of pain. Before deploying such technologies in the clinical setting, it is imperative to conduct thorough ethical scrutiny, despite the claims of what they hold. Medical professionals and health organizations should make concerted effort to ensure the deployment of transparent, explainable, and robust data-driven FRT for pain assessment in the clinical setting. This will promote quality care and equitable outcomes in nonverbal patients. When this occurs, technology companies and AI developers will recognize the need to evaluate the current AI/ML pipeline in order to assure quality demographically-balanced data collection, algorithmic accountability, and robust development of AI-driven FRT for clinical deployment.

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Patterns of Clinical Ethics Consultation Before and After the Initial COVID-19 Surge in New York City

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ABSTRACT: Background: Since the COVID-19 pandemic, clinical ethics consultation services have faced new challenges such as medical decision-making in the setting of unprecedented resource and staffing shortages and increased public mistrust of the healthcare system. This study aims to analyze shifts in consultation patterns due to long-lasting consequences of the pandemic in a healthcare system in New York City. We hypothesized an increase in consults placed for refusal of medical treatment due to heightened public distrust. Methods: We used the clinical ethics consultation service database to extract data on volume and reason for consult. Consults placed between 2015 and 2021 were included, except those placed during the height of the COVID-19 surge in March and April 2020. Chi-squared tests were used to compare the proportion of consults requested for each ethical issue between pre-COVID and post-COVID cohorts. Logistic regression was used to compare proportions of consults between the cohorts while controlling for confounding demographic variables. Results: 547 consults in the pre-COVID cohort and 215 in the post-COVID cohort were included. There was no significant difference pre- and post-COVID in the proportion of ethics consults placed for refusal of medical care in either the unadjusted or adjusted analysis (27% and 24% respectively). There were some statistically significant differences in other categories of consultation, however the absolute numbers were small. Conclusions: Our findings did not support the hypothesis that increased public mistrust in the post-COVID era has increased consultations related to refusal of recommended medical care. Perceptions of increases in refusal of medical care may be related to overall increases in clinician moral distress and emotional fatigue.

KEYWORDS: Clinical Ethics; Ethics Consultation; Treatment Refusal; COVID-19

Introduction

Hospital staff, patients, and families increasingly rely on clinical ethics consultation services to discuss the moral dilemmas and ethical conflicts that emerge during the course of a patient's care.[1,2] Ethics consultation services often consist of an onsite team of clinical consultants to address such issues as they arise, including those surrounding patient autonomy, surrogate decision making, and end-of-life care.[3]

Since the declaration of COVID-19 as a global pandemic in March of 2020 by the World Health Organization, ethics consultation services of hospitals throughout the country proved integral to healthcare delivery as clinicians faced new challenges from heightened moral distress at the bedside to difficult questions of resource allocation at the institutional level.[4-6] Early in the pandemic, clinicians practicing in New York experienced increased ethical burdens such as concerns of medical futility and uncertainties about a novel disease.[7-9] It is important to examine the nature of ethics consult requests during this period to prepare clinicians and consult services in navigating these dilemmas in public health crises as well as ordinary care.

Additionally, the pandemic has furthered scientific skepticism and a lack of confidence in medical institutions among the general public. This can be attributed to several factors, including the wide spread of misinformation and the influence of political sentiments and conspiracy theories on public perceptions and individual beliefs.[10-12] The effects of medical mistrust have been seen throughout the pandemic, such as in the varied responses to protective measures against COVID-19,[13,14] and thus could also have broader impacts on medical decision-making and ethical challenges in the hospital setting. Bioethics consultants are sometimes called when a patient is refusing recommended medical treatment, such as surgical intervention, diagnostic workup or medication. These refusals are particularly troubling to the medical team when the patient is not near the end of life and when treatments are likely to have clinical benefit.

During the initial surge in March and April of 2020, the clinical ethics service was engaged in other activities including scarce resource allocation planning and addressing staff moral distress. This study focuses on individual patient consults, looking at long-term changes in patterns of consultation, specifically excluding the period of March and April 2020 when there were marked and temporary changes in ethics service activities.

While some studies have reported on the unique ethical dilemmas encountered by ethics consultation services during the initial surge of the pandemic[7-9,15,16,] this study will examine an extended period of ethics consults at a large urban healthcare systems in New York City to identify any lasting shifts in consultation patterns due to the longer-term consequences of the pandemic such as reduced trust.

The purpose of this study was to 1) characterize the demographic information, reason for consultation, and ethical issues of a busy clinical ethics consult service from 2015 to 2021 and 2) analyze the changing trends in the proportion of consults placed for different ethical issues, primarily refusal of medical care, because of the COVID-19 pandemic. Due to the heightened public distrust, we hypothesized that there would be an increase in consults placed for refusal of medical treatment.

Methods

This study was approved by the Albert Einstein College of Medicine/Montefiore Medical Center Institutional Review Board (protocol #2018-9087).

Setting

The Montefiore-Einstein Center for Bioethics provides consultation services to Montefiore Medicine, which includes three acute care hospitals serving adults and one children's hospital in the Bronx, NY, and multiple outpatient primary and specialty care clinics. Together the acute care hospitals have approximately 1,500 beds. The Center's clinical ethics consultation service consists of one full-time and three part-time clinical ethicists and one clinical ethics fellow. Any staff member, patient or family member may request a consult. Ethics consultants review the clinical information, discuss cases with all stakeholders and make recommendations which are documented in the chart. The hospital system was hard-hit during the initial COVID-19 surge of March and April, 2020, requiring a tripling of intensive care unit (ICU) bed capacity.[17]

Data Source

The Center maintains a REDCap database of consultation activities for clinical and quality improvement purposes. Demographic information was obtained using Montefiore Health System's electronic health record (EHR; Epic platform; Epic Systems Corporation) and documented in REDCap. Clinical ethics consultation cases were also documented in REDCap, including reason for consult, advance directives, relevant medical history, and consult outcome. For each case, additional variables including comorbidities, socioeconomic status, insurance status, and discharge disposition were obtained using a replica of Montefiore's Clinical Information System using healthcare surveillance software Clinical Looking Glass (CLG); Emerging Health Information Technology; Yonkers, NY. REDCap data was matched with CLG data using the patient's medical record number and the date of the consult. To ensure accuracy, the patient's date of birth, which was a common variable to both datasets, was used to cross-check.

Taxonomy

Each consult input into the RedCap database was assigned ethical issue(s) by the staff (bioethicists, student researchers, etc.). Options available when inputting information into the database for the ethical issue(s) include discharge planning, advance directives, brain death, confidentiality, decision-making capacity, foregoing life-sustaining treatment, HIV partner notification, informed consent, medical error, medical futility, miscommunication/misunderstanding, organ donation, pain control, a patient without a surrogate, pediatric assent/parental permission, quality of care, quality of life, refusal of medical care, resource allocation/utilization, resuscitation status, and surrogate decision making, transgender health, truth-telling/disclosure of information, and "other." The categories were not used in a mutually exclusive way (i.e., a patient may be assigned more than one ethical issue per consult) by all technicians who input the information. Chart review was utilized to determine the ethical issue(s). Student researchers entered data into RedCap from clinical documentation by the ethics team and from chart review. Ten percent of consults entered by student researchers were reviewed and verified by one of the clinical ethicists.

The category of "refusal of medical care" included patient refusals of surgical interventions, diagnostic tests and medications. Frequent examples included refusals of hemodialysis who were otherwise not near end of life, refusals of lower extremity amputation, and refusals of central line placement, to name a few. It did not include patients who declined life-sustaining treatment at end-of-life. Issues regarding life-sustaining treatment were coded separately in the "forgoing life-sustaining treatment" category.

Service Structure/Setting

The Center's clinical ethics consultation service consists of one full-time and three part-time clinical ethicists (one at 0.2 FTEs and two at 0.1 FTEs) and one full-time clinical ethics fellow.[18-19] Ethics consultants review the clinical information, discuss cases with all stakeholders either in person or over the phone, and make recommendations that are documented in the chart. We use the single consultant model and cases are discussed among ethicists at weekly conferences and as needed. Embedded rounding models are not used by the service.

The acute care hospitals have approximately 1,500 beds. The smallest has 360 adult patient beds including a medical ICU with 15 beds. The largest contains 726 adult patient beds including five ICUs made up of 58 beds. The last has 431 adult patient beds including two ICUs containing 32 beds. Ethicists are shared between all centers with one ethicist and one fellow on call, traveling to the hospitals or ICUs as needed. The bioethics center is located at the largest acute care hospital. During the first year of the COVID-19 pandemic, the workflow was temporarily changed from in person at the center to work from home.

Study Population and Inclusion Criteria

This study analyzed consults placed from December 2015 (the inception of the clinical ethics consults database) to November 2021. Consults placed after November 2021 were not included in this study as a bioethics order in the electronic health record became available during this time, which is a factor that increased overall consult volume and may have changed consult patterns.

Consults were stratified into pre- and post-COVID cohorts. The pre-COVID cohort included consults placed before March 2020 and the post-COVID cohort included consults placed May 2020 and onwards. Consults placed between March and April 2020 were excluded because this was during the surge of the pandemic, another factor that may have affected consult pattern.

Demographics and Clinical Variables

Demographic data included age, gender, race, and ethnicity. Clinical characteristics included length of hospital stay and comorbid conditions.

Statistical Analyses

Statistical analyses were performed using Stata (version 17.0) and Microsoft Excel for Mac (version 16.64). Descriptive statistics were used to report patient demographic characteristics, including median (IQR) for age. Other characteristics including gender, race, and ethnicity were reported as n (% of cohort). The chi-square test was used to compare the proportion of consults requested for each ethical issue between pre-COVID and post-COVID cohorts. Proportion of consults was used as the primary metric as there was no significant difference in volume of consults over time between the two cohorts using a t-test of difference in mean monthly consult volume between the cohorts. Logistic regression was used to measure the association between cohort status while controlling for potential confounders including age, race, ethnicity and Charlson comorbidity score. A large number of ethics consults are for refusal of hemodialysis and lower extremity amputation, and renal disease and peripheral vascular disease are more prevalent in African Americans, we included renal disease and peripheral vascular disease as potential confounders in the adjusted model. For all t-tests, chi-square tests, and logistic regression, a p-value of < 0.05 was used to indicate statistical significance.

Results

Of the 783 total consults placed between December 2015 and November 2021, 762 consults were included in the final analysis. Four consults were excluded from March and April 2020, and 17 consults were excluded due to missing or erroneous patient identifiers and/or consult date. There were 547 consults in the pre-COVID cohort and 215 consults in the post-COVID cohort.

Patient Characteristics

The median age of patients that received consults was 66.0, with slightly more than half male (56%). Seventeen percent of the patients were White, non-Hispanic, 34% were Black, non-Hispanic, 29% were Hispanic, and 20% were listed as unknown or other race/ethnicity. Patients who preferred English were 82%, 12% preferred Spanish, and 6% preferred another language. The mean length of stay was 35 days, with internal medicine as the top admitting service (71%). The characteristics of both the pre-COVID and post-COVID cohorts reflected the total pool, and there was no significant difference between the two cohorts **(Table 1)**.

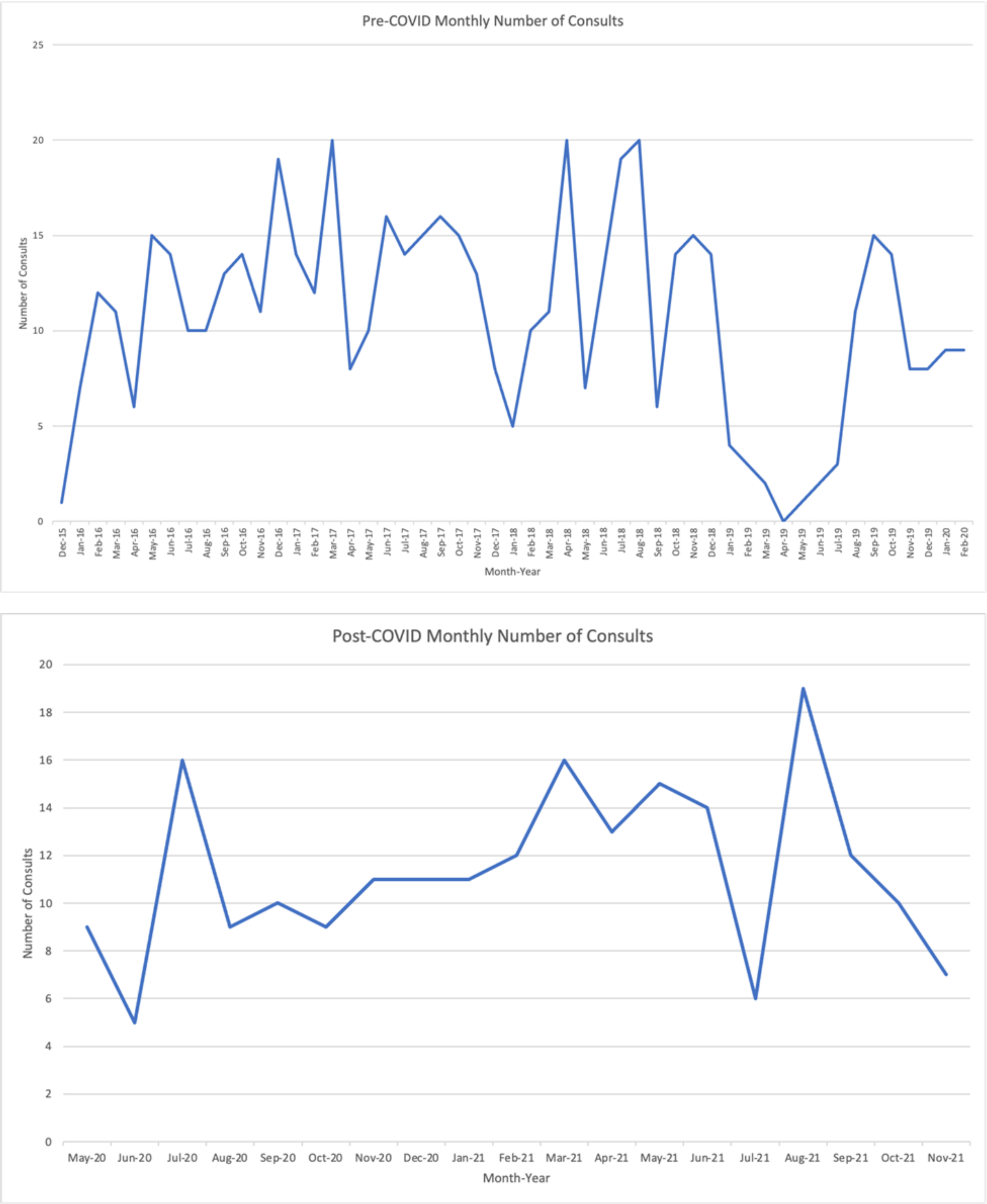
TABLE 1: Patient Characteristics

	Total	**Pre-COVID**	**Post-COVID**	**P-value**
Total consults, n	762	547	215	
Age in years, median (IQR)	66.0 (55.0-77.0)	66.0 (54.0-76.0)	66.0 (55.5-78.0)	<0.05
Gender				
Male, n (%)	426 (55.91)	295 (53.93)	131 (60.93)	<0.05
Race				
American Indian or Alaska Native, n (%)	2 (0.26)	1 (0.18)	1 (0.47)	<0.05
Asian, n (%)	13 (1.71)	8 (1.46)	5 (2.33)	<0.05
Black or African American, n (%)	283 (37.14)	202 (36.93)	81 (37.67)	<0.05
White, n (%)	152 (19.95)	109 (19.93)	43 (20.00)	<0.05
Other, n (%)	312 (40.94)	227 (41.50)	85 (39.53)	<0.05
Ethnicity				
Non-Hispanic, n (%)	445 (58.40)	313 (57.22)	132 (61.40)	<0.05
Hispanic, n (%)	220 (28.87)	151 (27.61)	69 (32.09)	<0.05
Unknown or Patient Refused, n (%)	97 (12.73)	83 (15.17)	14 (6.51)	<0.01
Preferred Language				
English, n (%)	626 (82.15)	452 (82.63)	174 (80.93)	<0.05
Spanish, n (%)	90 (11.81)	61 (11.15)	29 (13.49)	<0.05
Other, n (%)	46 (6.04)	24 (6.22)	12 (5.58)	<0.05
Hospital Stay				
Length of stay in days, mean	34.68	35.35	33.06	<0.05
Top 3 admitting service, n (%)	Medicine (70.7) Cardiology (5.0) Surgery (3.4)	Medicine (69.4) Cardiology (4.6) Pediatrics (3.5)	Medicine (73.8) Cardiology (6.1) Family Med (4.7)	<0.05

Consultation Characteristics

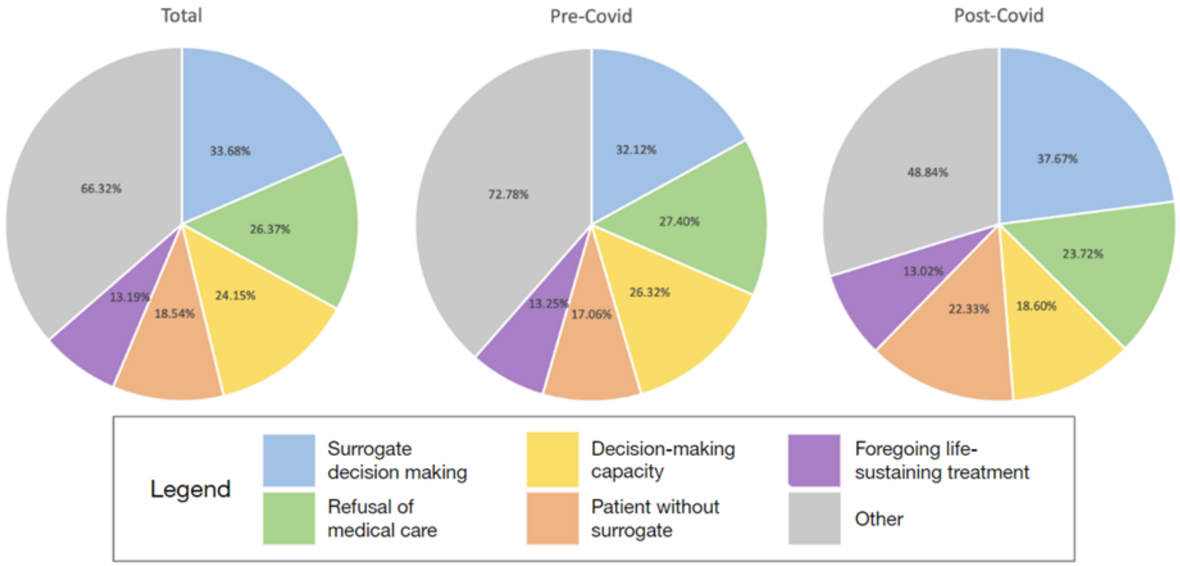
There was no difference in the median number of monthly consultation cases between the pre-COVID and post-COVID cohort (11 vs 11, p = 0.66) **(Figure 1)**.

FIGURE 1: Pre- (top) and post-COVID (bottom) monthly number of consults



There was also no significant difference in consultation characteristics between the two cohorts, including requesting service (e.g. Medicine, Cardiology, Surgery) code status, and available advance directives. The top five reasons for consults were the same in pre-COVID and post-COVID periods. These were surrogate decision making, refusal of medical care, decision-making capacity, patient without surrogate and foregoing life-sustaining treatment **(Figure 2)**.

FIGURE 2: Most common reason for consults in all cases (left), pre-COVID (middle), post-COVID (right)



There was no significant difference between pre- and post-COVID cohorts in the proportion of ethics consults placed for refusal of medical care ($p > 0.05$) **(Table 2)**.

TABLE 2: Unadjusted analysis for refusal of medical care and other ethical issues

Primary ethical issue	**Total**	**Pre-COVID**	**Post-COVID**	**p-value**
Refusal of medical treatment, n (%)	200 (26.25)	149 (27.24)	51 (23.72)	>0.05
Surrogate decision making, n (%)	258 (33.86)	177 (32.36)	81 (37.67)	>0.05
Decision-making capacity, n (%)	185 (24.28)	145 (26.51)	40 (18.60)	**<0.05**
Patient without surrogate, n (%)	141 (18.50)	93 (17.00)	48 (22.33)	>0.05
Foregoing life-sustaining treatment, n (%)	101 (13.25)	73 (13.35)	28 (13.02)	>0.05
Discharge planning, n (%)	73 (9.58)	61 (11.15)	12 (5.58)	**<0.05**
Quality of care, n (%)	40 (5.25)	40 (7.31)	0 (0)	**<0.01**
Quality of life, n (%)	33 (4.33)	29 (5.30)	4 (1.86)	**<0.05**

The same result was seen in an adjusted analysis controlling for confounders including age, gender, race, ethnicity, Charlson comorbidity score, renal disease and peripheral vascular disease ($p = 0.2$) **(Table 3)**.

TABLE 3: Adjusted Analysis for Refusal of Medical Care

	Odds Ratio	**95% CI**	**p-value**
Post-COVID	0.83	0.56-1.23	0.36
Age	0.99	0.98-0.99	**<0.01**
Male	1.32	0.94-1.86	0.11
American Indian or Alaskan Native	12.2	1.32-114.12	**<0.05**
Asian	1	(omitted)	(omitted)
African American	1.31	0.87-1.97	0.20
Other/unknown	0.87	0.53-1.41	0.56
Hispanic/Latino	1.40	0.90-2.19	0.14
Charlson Score	0.95	0.89-1.01	0.10
Renal disease	1.78	1.19-2.67	**<0.01**
Peripheral vascular disease	2.02	1.26-3.26	**<0.01**

There was a significant decrease in ethics consults pertaining to decision-making capacity, discharge planning, quality of care and quality of life ($p < 0.05$) in the post-COVID cohort. However, the consult volume for discharge planning, quality of care and quality of life were relatively small ($n < 100$ for each category), making these findings more difficult to interpret. There was no significant difference in the other most common reason for consults. Stratifying these results by hospital site and unit type revealed that the decrease in consults for decision-making capacity was seen across all sites and unit types **(Table 4)**. There were several consults (< 5 consults total) related to COVID-specific novel issues including requests for non-beneficial treatments such as ivermectin, and conflicts that arose related to visiting restrictions.

Discussion

This study did not support the hypothesis that there would be an increase in consults placed for refusal of medical treatment following the start of the pandemic. There was no significant difference in this consult category between the two cohorts, and although there were anecdotal accounts of seeing an increasing number of patients refuse care, the proportion of consults placed for refusal of medical care was not impacted by COVID-19. Factors such as heightened moral distress among healthcare staff [20-22] may explain the discrepancy between perceptions of increased refusal of care and the data. The burden felt by clinicians was evident since the initial surge of the pandemic, from seeing significantly increased morbidity to navigating a state of uncertainty and ambiguity while still trying to provide optimal care for patients.[23]

Political polarization and widespread misinformation may have increased the level of entrenchment of patients and families in their refusals. These challenges coupled with increasing sentiments of public distrust and a shifting political landscape may have impacted the personal experiences of clinicians with patient refusals, leading to the impression that the volume of these cases had increased. While the num-

TABLE 4: Unadjusted Analysis for Refusal of Medical Care and Other Ethical Issues by Unit

	Refusal of Medical Treatment		**Surrogate decision-making**		**Decision-making capacity**		**Patient without a surrogate**		**Forgoing life-sustaining treatment**	
N(%)	Pre-covid	Post-covid	Pre-covid	Post-covid	Pre-covid	Post-covid	Pre-covid	Post-covid	Pre-covid	Post-covid
Hospital 1	89 (28.0)	31 (26.7)	97 (30.5)	39 (33.6)	**97 (30.5)**	**26 (22.4)**	63 (19.8)	31 (26.7)	39 (12.3)	16 (13.7)
Hospital 2	37 (23.8)	15 (20.5)	68 (43.9)	30 (41.1)	**68 (43.9)**	**11 (15.1)**	28 (18.1)	12 (16.4)	23 (14.8)	7 (9.6)
Hospital 3	4 (20.0)	5 (23.8)	3 (15.0)	10 (47.6)	3 (15.0)	3 (14.2)	1 (5.0)	5 (23.8)	4 (20.0)	3 (14.3)
General medical or surgical	113 (33.9)	37 (24.8)	126 (32.1)	57 (38.3)	**126 (32.1)**	**26 (19.4)**	70 (17.8)	33 (22.1)	42 (10.7)	22 (14.8)
Telemetry	6 (33.3)	4 (33.3)	8 (44.4)	4 (33.3)	8 (44.4)	2 (16.7)	1 (5.5)	1 (8.3)	3 (16.7)	2 (16.7)
Step-down	3 (30.0)	1 (33.3)	1 (10.0)	2 (66.6)	1 (10.0)	0 (0.0)	2 (20.0)	1 (33.3)	0 (0.0)	1 (33.3)
ICU	19 (18.1)	8 (20.0)	38 (36.2)	16 (40.0)	**38 (36.2)**	**6 (15.0)**	19 (18.1)	11 (27.5)	**22 (37.6)**	**3 (7.5)**

bers of refusal cases remained the same, the complexity and level of engagement required by the clinical ethics service increased as did our perception of the team's level of distress. These factors are difficult to capture in the current data set.

The COVID-19 pandemic also altered many factors of patient care. While general trends in reasons for consults did not appear to change throughout this study period, consult cases may have been complicated by additional factors and challenges that emerged due to the pandemic, such as changed family structures and newly enforced visitor restriction policies. Restrictions on visitors have been shown to greatly impact the health and wellbeing of admitted patients including decreased nutritional intake and mental health consequences as well as new ethical dilemmas such as inadequacy of family understanding and participation in a patient's care stemming from the lack of dialog between providers, patients, and their loved ones.[24-25] In addition to heightened restrictions, the phenomenon of family clustering (i.e., multiple individuals of a household contracting COVID-19) during the pandemic led to a scarcity of available surrogate decision-makers for those incapacitated.[26] While not significant, there was a slight uptick (5%) in the proportion of ethics consults placed for both surrogate decision making and patient without surrogate, which could have been impacted by lack of quality communication avenues that added difficulties in decision-making for family members.[27] In addition, the Bronx saw the highest number of deaths (224 per 100,000 population) related to COVID-19 among the New York City boroughs.[28] As a result of the high mortalities during the pandemic, many families may have been destroyed, leaving more hospitalized patients without close family members to act as surrogate decision-makers.

Results of the secondary analysis were generally as expected. Patients with renal disease and peripheral vascular disease were more likely to receive a consult for refusal of medical care due to the higher rates of refusal of hemodialysis and lower extremity amputation, which are psychologically and physically burdensome interventions. Age was inversely related to refusal of recommended care. This likely reflects the higher rates of consultation for refusal of recommended care among patients with neurodegenerative diseases associated with aging. The increased likelihood of American Indian/Alaskan Native (AI/AN) patients to receive a consult for refusal is likely spurious due to the small number of AI/AN patients in our sample. There were no other significant racial or ethnic differences.

Although it is reassuring that the proportion of consults for refusal of medical care did not increase over time, these consults remain common. This hospital system serves a diverse population of patients, many of whom have encountered structural, institutional and interpersonal racism in healthcare settings. Ongoing efforts to build trust are imperative to improve health equity.

Limitations

One limitation of this study is that it is a single-center observation study and results may not be generalizable to other ethics consult services with different consultation processes and patient populations. Additionally, given the observational nature of the study, we were unable to control for temporal trends in bioethics consultation unrelated to the pandemic. For example, incoming house staff may have increased bioethics education, making them more aware of the consultation service. In addition, some changes in ethics service practice remained after the initial surge, including a closer collaboration and more frequent meetings with the hospital's risk management and legal teams, which may result in a non-significant increase in referrals directed from the risk and legal teams. However, this collaboration is unlikely to change the patterns of consult requests from clinicians. There were no significant changes in the ethics consultation service staff during the study period, minimizing the risk of bias due to confounding temporal trends. Although quality control was undertaken by reviewing and validating a subset of data entry, some differences in categorization between individuals entering data may remain. For example, for patients who lack capacity and lack a surrogate decision-maker, ethicists would code the consult in the category “a patient without a surrogate” if the patient was already determined to lack decision-making capacity for the decision at hand. However, some may have added the code “decision-making capacity” because this was an additional component of the case. Differences in coding between coders may explain the differences in this category over time, given that the difference was seen across all hospitals and sites, making a difference in referral patterns of particular units unlikely.

Conclusion

Given the changing landscape of ethical issues as the pandemic evolved from an acute disaster to a chronic stressor, we expected the patterns of clinical ethics consultation to change over time. We found that anecdotal impressions of increases in patient refusal of recommended care were not substantiated by the data. These impressions might be due to increased moral distress among clinicians. Clinical ethics consultants can play an instrumental role in helping clinicians manage moral distress, thus mitigating ongoing harms to healthcare teams. Further research should investigate whether changes in family structure have caused increased complexity in surrogate decision-making.

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Forced Urinary Catheterization by Nurses for Police: “Reliable and Accepted” or “Wanton Misconduct”

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ABSTRACT: Emergency nurses often face ethical dilemmas in their interactions with law enforcement. One such dilemma arises when police order emergency nurses to forcibly catheterize a resisting arrestee in order to collect a urine specimen for the sole purpose of obtaining evidence of drug or alcohol use. Although the procedure is invasive and serves no medical purpose, police argue it could produce evidence to protect public health and safety by keeping dangerous drivers off the road. This article assesses the ethical implications of the practice for nurses through a review of clinical literature, state laws, and court cases. It concludes that the practice violates nurses’ principal ethical obligations to hold a patient’s welfare as our primary commitment and does little to promote public health and safety. Therefore, hospitals and professional nursing organizations should issue policies and position statements to clarify for nurses, judges, law enforcement officers, and legislators that internally catheterizing unwilling people for the sole purpose of obtaining urine samples as evidence for police is antithetical to the values of nursing.

KEYWORDS: Catheter; Urine; Ethics; Involuntary; Police; Law Enforcement

Introduction

Jamie Lockard was pulled over by Officer Brian Miller for speeding and ignoring two stop signs. He failed a field sobriety test, refused blood and urine testing, and was arrested. Officer Miller secured a warrant to “obtain and remove a blood and urine sample” with “the necessary and proper assistance.”[1] He drove Mr. Lockard to a nearby hospital and presented the warrant. There, Mr. Lockard willingly provided a blood sample but was either unable or unwilling to provide a urine sample. He refused to consent to – and had no medical need for – urethral catheterization. But an emergency department physician and, ostensibly, a court order[a] instructed Nurse Deborah Walston to catheterize Mr. Lockard. What should Nurse Walston have done?

Neither Mr. Lockard’s ordeal nor Nurse Walston’s ethical dilemma is unique. Between 2010 and 2020, at least 20 plaintiffs in 15 separate court cases sued nurses, police officers, hospitals, and others based on allegations of forced urethral catheterization at the direction of law enforcement but at the hands of nurses.[b] To date, no nursing authority or regulatory body has opined on these cases from the perspective of nursing ethics. This suggests that it is an open question in the nursing profession whether forced urethral catheterization ordered by law enforcement but not medically indicated is an appropriate and ethical use of a nurse’s license and training.

As explored below, clinical studies show that urinary catheterization can be extremely painful, and best practices to mitigate pain and injury are unavailable when the patient is physically resisting the procedure. Although urine samples may produce some evidence useful to law enforcement, laws about impaired driving in virtually every state already penalize – and protect the public from – drivers who refuse to voluntarily provide a sample. More than one federal court has determined that the practice violates an arrestee’s rights under the United States Constitution. Nursing leaders ought to follow suit and acknowledge that performing urinary catheterization on an unwilling person for the sole purpose of obtaining evidence for law enforcement is antithetical to the values of nursing.

Pain and Injury

Pain. Urethral catheterization is a common procedure in the emergency department and often painful. One reason is simply anatomical: the catheter must pass through the external sphincter, which contains a high concentration of afferent nerves.[2,3] Systematic reviews of studies that assess pain associated with catheter insertion have concluded that “males and females both find urethral catheterization painful”[4] and that “the level of pain felt

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[a] In Mr. Lockard’s case, it is unclear whether the warrant’s directive to “obtain and remove . . . urine” in fact authorized forced urethral catheterization. Warrants in other cases discussed below are similarly vague. For example: “search ‘the person of Gena Alvarez . . . [for a] Urine Sample’” (Riis v. Shaver, 2020, p. 18); “search/seize the person of Aaron Peters and transport him to the Wagner Community Hospital to have a sample of his Urine taken buy [sic] reliable and accepted method, in medically approved, reasonable manner” (Riis v. Shaver, 2020, p. 13); “‘obtain and remove blood or other body fluid sample(s) . . . [and] use reasonable force to obtain such sample(s)’” (Ballheimer v. Batts, 2020, p. 8).

[b] The full list of cases, some of which include multiple plaintiffs, is presented in the Appendix. Judges in four of the cases ultimately found that the plaintiff’s catheterization did have a medical purpose separate from, or in addition to, its police purpose (Hyatt v Falcon, 2020; Favela v. City of Las Cruces, 2019; Gold v. City of Sandusky, 2018; Pratt v. Carroll, 2015). One plaintiff alleged he was threatened with forced catheterization to compel compliance (Abdo v. Larson, 2020).

can rise to severe levels." Singer et al. (1999) asked patients in the emergency department to rate the pain of various procedures. When responses were aggregated and averaged, urethral catheterization ranked fourth out of 15 procedures, on a par with fracture reduction, abscess drainage, and nasogastric tube insertion. In a more recent study, emergency physicians agreed: they ranked urinary catheterization third after lumbar puncture and abscess incision.

Injury. Catheter insertion can also cause urethral trauma. People who are "conscious and without systemic analgesia during the attempted catheterization" (e.g., arrestees) are at an increased risk because they "offer[] resistance to catheter placement due to reflexive sphincter contraction as the catheter encounters the membranous urethra and urinary sphincter."[8]

Even without active resistance from the patient, there are numerous opportunities for physical injury. A catheter that is too wide can damage urethral tissue, which may lead to infection, abscess, and scarring.[9] A catheter that is too narrow may coil inside the urethra.[10] Friction during insertion can create a stricture – a narrowing of the urethra due to scar tissue – which can make urination chronically difficult and painful and may require surgical repair or long-term catheterization.[11] And pressure from the catheter tip against the wall of the urethra during insertion can create a false passage – a recess or impression branching off the urethral lumen.[12,8]

Best Practices. To reduce the pain and risk for injury associated with catheter insertion, clinical organizations have developed evidence-based guidelines and algorithms.[13,14] Practitioners have also published recommendations based on their own clinical experiences.[10,15] But because these best practices generally require the cooperation or compliance of the person being catheterized, they are largely unavailable to a nurse who is forcibly catheterizing a struggling and unwilling arrestee.

For example, during penile catheterization, proper tension, angle, grip, and pressure are key to mitigating pain and trauma: "the penis must be constantly stretched gently upwards while catheterizing to prevent urethral wall folding"[16] and should be elongated and held at a 60- to 90-degree angle in order to minimize curves or bends between the external and internal urethra.[10,15] The nurse's grip should be firm enough so that the penis is taut but gentle enough not to cause compression, because a compressed urethra may obstruct the catheter and cause friction, pain, and injury.[9,10] "Forceful manipulation during catheter insertion" is an "important contributing factor[] for the development of urethral strictures . . . ."[17] And because the external sphincter is "generally spastic" and "may go into spasm as the tip of the catheter passes deep in the urethra," insertion should be "gentle, smooth, and continuous."[16] Consider the difficulty of achieving the proper angle, tension, grip strength, and insertion pressure while an arrestee is actively struggling against the procedure.

Some evidence supports that bearing down, as if urinating, can reduce the pain of catheter insertion by relaxing the external sphincter.[2,10,14] Other published literature recommends breathing and relaxation methods.[15,18] But both strategies require the cooperation and active participation of the person being catheterized and are of little use in the context of forced catheterization.

Lubricant is universally recommended to minimize friction,[9,13-16] though there is not wide agreement about the best type of lubricant, volume, or method of application. Some guidelines suggest that lidocaine gel be instilled into the urethra several minutes before catheterization, and a penile clamp is sometimes suggested to keep the lidocaine in place.[2,14,15] But literature reviews and clinical studies have found the evidence for local analgesia lacking.[6,19]

In sum, urethral catheterization ranks among the more painful procedures in the emergency department. Pain and risk of injury are higher when the person being catheterized actively struggles against the procedure because mitigating measures are unavailable. Although no study has examined the pain and injury associated with forced, medically unnecessary catheterization, results of the practice have been captured in video evidence, eyewitness accounts, and victim testimony from more than a dozen federal trials in which arrestees challenged the procedure. Judicial opinions in these cases describe the encounters in excruciating detail, often narrated or quoted directly from police body camera footage. For example:

1. 03:59 - 04:34: Four officers hold Peters down on the hospital bed.
04:40: The nurse begins the catheterization while the officers hold Peters down.
04:41 - 05:21: Peters screams in obvious pain repeatedly.

Peters testified that he urinated blood for a week after the catheterization, and that it felt like he was peeing 'razor blades.' He felt like the police ‘raped’ him and he still feels that way.[20]

2. Alvarez described waking up to bright lights and people holding her down, people taking off her clothes, ‘begging’ and ‘screaming’ for them to stop, and ‘screaming at’ her dad ‘to stop’ even though he wasn’t there. She testified that being held down and catheterized reminded her of being sexually abused by her father and his friends. She also said that she felt a ‘huge pressure pain inside of me’ after the catheterization, that she had pain from the catheterization for four to six weeks, and that she feels humiliated and degraded.[20]

3. [Officers] handcuffed Plaintiff to the surgical table, pulled his pants down, and held Plaintiff’s legs in a spread-eagle position. Deputy Drake described Plaintiff as ‘grunting’ and ‘showing pain’ as the catheter was inserted.”[21]

4. The catheterization then proceeded in a forceful manner, during which Hernandez yelled ‘no’ and screamed from the pain as nurse John Doe 2 and security officer John Doe 3 held him down and nurse John Doe 1 forced the catheter into Hernandez’s penis and then yanked it out, causing serious pain and injuring the urethra.[22]

Yet the practice persists. Although 20 plaintiffs were identified in this review of cases, forced catheterization is likely more common than that. Lawsuits reflect the experiences of only the few victims who have the resources, opportunity, and willingness to take legal action. One doctor testified in court that he authorized more than 10 forcible catheterizations for law enforcement in a five year period.[20] In that same case, an officer testified to a widespread belief among his fellow officers that catheterization is mandatory if an arrestee does not voluntarily provide a urine sample pursuant to a warrant.[20] That nurses continue to participate is likely due, in part, to the legal and regulatory morass that emergency nurses face in this circumstance and the lack of clear directives from nursing leaders.

Legal and Regulatory Morass

Nursing practice is regulated by multiple overlapping governing bodies and sources of authority. Unfortunately, in the case of forced, non-medical catheterization, the sources of authority most accessible and relevant to the nurse provide little guidance. Many hospitals have no written policy or procedure that directly addresses forced, non-medical urethral catheterization. State Nurse Practice Acts and related regulations are generally silent on the issue as well. If a state board of nursing initiates administrative action or suspends the license of a nurse who performs the procedure, those records are generally stored in state-specific databases that are not readily searchable, which makes it difficult for others in the profession to learn of the board’s view. The American Nurses Association (ANA) does not address the issue in its Code of Ethics for Nurses. And although the ANA has issued dozens of position statements – on issues ranging from fluoridation of public water systems to the therapeutic use of marijuana[23] -it has not issued one about forced, non-medical catheterization by emergency nurses for law enforcement. As a result of this void in guidance from leaders in the nursing profession, the laws and sources of authority that do speak to the issue of forced catheterization often speak only indirectly to the roles and responsibilities of nurses.

State Laws. All fifty states and the District of Columbia have enacted so-called “implied consent” laws to reduce driving under the influence of drugs and alcohol (DUI).[24-26] These laws aim to prevent impaired drivers from withholding evidence of their crimes by simply refusing a chemical test of breath, blood, or urine.[24] Under these laws, “the act of driving itself indicate[s] that a driver ha[s] consented to chemical testing for intoxication,”[24] and a driver who refuses to provide a sample for testing will have their license suspended for anywhere from 30 days to several years, depending on the state and the driver’s history.[25,27] (Only one state, Wyoming, does not impose automatic license suspension for refusal to test).

But the implications of these laws for nurses vary from state to state. In some states, if a driver refuses to provide a sample, then a chemical test “shall not be given.”[28] Other states allow chemical testing over a driver’s objection if a suspected DUI causes physical injury.[29] State laws also differ as to who is permitted (or required) collect the samples: in some states, only a healthcare professional may perform venipuncture but police are permitted to collect urine;[30] in others, police are trained in phlebotomy and may perform venipuncture on an arrestee.[31]

When police bring an arrestee to a hospital and request sample collection, some state laws appear to require that the nurse comply. In Washington, DC, for example, the “medical professional shall collect the specimen,"[32] and in Hawaii the tests "shall be administered at the request of a law enforcement officer."[33] In South Carolina, on the other hand, police cannot require a nurse or other healthcare professional to draw blood or obtain a urine sample.[34]

In some states, a nurse who collects urine for law enforcement is shielded from liability. Laws in these states aim to protect nurses from lawsuits brought by the arrestee, unless the nurse is "reckless,"[34] grossly negligent,[35] or acts with "willful or wanton misconduct"[36] when collecting the sample. Some states require that urine samples be collected with respect for the arrestee's privacy and to "maintain the dignity of the individual involved."[37] Forced catheterization without medical purpose is arguably inherently reckless, wanton, and a flagrant violation of privacy and dignity given the unavoidable pain, psychological trauma, and heightened risk for physical injury. But if these prohibitions against reckless and wanton actions were intended to ban forced catheterization for law enforcement, they could have done so explicitly. Instead, their implications for nurses remain ambiguous, and they contribute to a patchwork of state laws that do little to clarify the rights and duties of nurses in the emergency department.

<u>Case Law</u>. When laws are ambiguous, it is often the role of judges and courts to interpret and provide clarity. Though courts have not clarified whether state implied consent laws permit forced catheterization, they have opined about the permissibility of forced catheterization in the context of the U.S. Constitution. In short, the Constitution (as interpreted by the U.S. Supreme Court) prohibits government actors, like police officers, from conducting "unreasonable searches and seizures" – e.g., without a warrant or with the use of "excessive force."[26] Moreover, under section 1983 of Title 42 of the United States Code, an individual (e.g., a nurse, police officer, etc.) who violates a plaintiff's constitutional rights while acting on behalf of a government entity can, in certain circumstances, be held individually liable and be required to pay damages to the plaintiff.[38] Thus, when arrestees like Mr. Lockard were forcibly catheterized, they sued the police and local government. Some also sued the hospitals and individual nurses who, they argued, acted on the police's behalf.

In court, defendants argue that forced catheterization is a valuable tool for law enforcement: a necessary means of obtaining evidence of illegal drug use in impaired drivers,[39] parolees,[20] and others[20] who refuse to provide a urine sample. Plaintiffs argue that urethral catheterization that is nonconsensual and has no medical benefit is so painful, traumatizing, and invasive that it amounts to an unreasonable search and seizure. Judicial opinions have been inconsistent.

Some courts have upheld the practice. For example, in the case of Mr. Lockard, the court found "the catheterizations itself was performed in a reasonable manner . . . by medical professionals in a hospital setting."[1] Despite the fact that Mr. Lockard refused the procedure, struggled against it, was handcuffed to the bed, with his ankles held down by police officers, and said it felt "'just as if somebody would take a burning hot coal and stick it up your penis,'" the court described the incident as an "accepted medical practice[]."[1] Another court wrote (perhaps paradoxically) that catheterization for no medical purpose can be performed in a "medically approved, reasonable manner."[40] Several courts have described the practice as "objectively reasonable"[40,41] and have concluded that forced catheterization is lawful and permitted even if "alternative less intrusive means" of evidence collection are available.[1,41,42]

Other courts, however, have found that the pain and indignity of forced catheterization outweigh the utility of a urine sample for law enforcement, especially when an arrestee has already provided a blood sample.[20,39] Any additional evidence available in urine – e.g., of certain drugs or their metabolites that are more readily detectable in urine than in blood – is of marginal benefit to the police.[20] "Although a blood test is inferior to a urine test in detecting past use of methamphetamine," one court noted, police are not entitled under the Constitution "to always get the best evidence, whatever the cost."[20] And when a blood sample is available, "[t]here is no community interest in involuntarily catheterizing [an arrestee] just to see if evidence exists to tack a drug ingestion charge onto an ironclad case of driving under the influence of alcohol."[20]

Despite more than a dozen cases and almost twice as many plaintiffs, several courts in recent years have lamented that the legal question is hard to resolve because of the "dearth of case law evaluating" this specific issue.[39,42] The U.S. Supreme Court has twice explicitly declined to opine.[26,43,c] And there is virtually no evidence that any individual nurse or police officer has been held per-

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[c] In two cases in which the Supreme Court opined about forced blood draws for police, the Court emphasized that those opin-

sonally responsible: for example, a federal court in Indiana in 2020 found officers violated an arrestee's rights when they ordered a nurse to forcibly catheterize him; but the court concluded that those officers "cannot fairly be held liable for" what the court described as their "bad guesses in gray areas."[39]

If the legal requirements are ambiguous to judges and law enforcement, then surely they are opaque to healthcare workers. As one court noted, "doctors and nurses are not Fourth Amendment gurus."[1] The lack of clear guidance from professional nursing organizations is thus compounded by the lack of clear directives from state laws and by inconsistent judicial opinions.

Ethics of Forced Non-Medical Catheterization

Courts have considered whether forced, non-medical catheterization violates an arrestee's rights under the U.S. Constitution. But whether the practice is consistent with a nurse's ethical duties is a separate question: the U.S. Constitution is not bound by the ANA Code of Ethics. Similarly, clinical literature and real-world evidence paint a grim picture of the experience of forced catheterization, but pain scales and human anatomy alone lack the ethical context needed for value judgment.

Nurses have ethical obligations to multiple stakeholders. The ANA Code of Ethics for Nurses states that "[t]he nurse's primary commitment is to the recipients of nursing and healthcare services – patient or client"[44] At the same time, the Code establishes ethical duties toward colleagues, organizations, the law, society at large, and to self.[44] Underlying all these obligations are the four principles of clinical ethics: autonomy, justice, beneficence, and non-maleficence.[45]

Here, the nurse's "primary commitment" is an arrestee in police custody. To forcibly catheterize that person over their verbal and physical objections violates that commitment and its underlying core principles. Whereas patients have the right to make decisions about their bodies and their care, forced catheterization strips the patient of that autonomy at a time when – under police custody – they are most in need of an advocate. Whereas nurses are bound to beneficence with a duty to care, catheterization for police offers no benefit to the patient's health. Perhaps most egregiously, it violates a nurse's duty of non-maleficence: evidence from eyewitness accounts, court-reviewed video footage, and victim testimony demonstrates that forced catheterization causes excruciating pain, risks short- and long-term bodily injury, and threatens emotional and psychological trauma. Clinical studies, nursing research, and healthcare guidelines show that these results, in a patient actively resisting the procedure, are virtually unavoidable. And in many instances, the arrestee neither sought nor needed medical attention and thus was not, in any meaningful sense, a patient; he or she was simply a person in police custody. In these instances, catheterization is not a nursing intervention. It is a torturous violation of autonomy that recruits America's "most trusted profession"[46] as a tool of police violence.

If justice demands that a nurse commit these violations – i.e., if a greater competing ethical duty justifies these failures of respect for autonomy, beneficence, and non-maleficence – then the competing duty must have outsize benefit. Here, the competing benefit does not meet that high bar. A nurse who catheterizes a resisting arrestee arguably fulfills an obligation to society and to public health by protecting the public from an impaired driver. But in reality, the nurse's action does little to further that interest.

First, the arrestee poses virtually no risk to others while they are in police custody. There is no imminent threat to the public that necessitates immediate, traumatic, and invasive action by the nurse. Second, police generally have already obtained other evidence of impairment before a urine specimen is collected. In the reviewed cases of forced catheterization, police had already conducted a field sobriety test or obtained breathalyzer and/or blood samples from the arrestee – i.e., evidence that can support restrictions and/or revocations of driver licenses, as well as criminal penalties. Third, the arrestee is almost certain to lose driving privileges (for months to years) even without catheterization because refusal to provide any sample is grounds for license revocation under state implied consent laws.[25] Although evidence of drugs in urine may support additional criminal penalties, laws in every state and the District of Columbia (except Wyoming) accomplish the goal of taking dangerous drivers off the roads if they

ions did not answer the related question about forced urinary collection for police: "[W]hile Wisconsin's and other implied-consent laws permit urine tests, those tests are less common . . . and we do not consider them here" (Mitchell v. Wisconsin, 2019, p. 3, n. 1); "[U]rine tests appear to be less common in drunk-driving cases than breath and blood tests, and none of the cases before us involves one" (Birchfield v. North Dakota, 2015, p. 6, n. 1).

refuse to provide a urine sample.

Until hospitals and nursing organization speak out against this practice, individual nurses may be left in the unenviable position of having to decide between complying with law enforcement and meeting their ethical obligations. Although the ANA Code of Ethics acknowledges a right to conscientious objection "[w]hen nurses are placed in circumstances that exceed moral limits," it also acknowledges that that right "may not insulate nurses from formal or informal consequences."[44] And a nurse who refuses to comply with a request from law enforcement for forced catheterization could be violating a state law, court order, or both.

At a minimum, hospital policies should insist that non-medical invasive urinary catheterization will not be performed without an arrestee's consent (or assent) unless a warrant specifically orders forced, non-consensual, invasive catheterization; vague court orders to "obtain urine" should not be presumed to require a nurse to physically and psychologically traumatize someone in their care. Hospital policies should also contemplate non-invasive means of collecting urine from unwilling arrestees, such as external urinary catheters (e.g., condom catheters, suction catheters, etc.).

But leaders in hospitals and professional organizations are well-positioned to end this practice altogether by clarifying for emergency department staff and for the criminal justice system that forced, non-medical catheterization is unacceptable to the nursing profession. The ANA routinely issues position statements to "guide the profession, amplify the views of nursing, and educate consumers and decision makers."[23] The ANA's guidance for nurses in correctional facilities comes close to addressing the issue with a passing reference in a discussion about maintaining professionalism with corrections staff: "[C]ollaborating with custody staff does not mean that correctional nurses participate in custody activities, such as the collection of purely forensic evidence, body cavity searches, disciplinary procedures, or the execution process."[47] But that guidance does not speak to the predicament of nurses outside correctional facilities. It also does not grapple with the ethical violation that forced catheterization represents or flatly prohibit nurse involvement.

A declarative position statement would provide a direct source of authority for emergency nurses to rely upon when faced with this specific circumstance. It would also send a clear message to judges and courts (who issue warrants and hear legal challenges) and to legislators (who can revise state laws) that the very people tasked with performing the procedure consider forced non-medical catheterization to be medically and morally wrong – not "medically approved"[40] or "objectively reasonable."[41] Hospitals and boards of nursing should also establish policies and rules to prohibit the practice and make it easier for nurses to refuse to participate.

Acknowledgement: Thanks, Rob, for showing me what perseverance looks like. And for always reminding me that every patient deserves our moral attention - because every patient is different.

APPENDIX: U.S. Federal Court Cases Involving Allegations of Forced, Non-Medical, Urethral Catheterization by Nurses for Law Enforcement, 2010-2020.

1. *Abdo v. Larson*, No. 4:17-CV-04079-LLP, 2020 WL 1139274 (D.S.D. Mar. 9, 2020).

2. *Ballheimer v. Batts*, No. 1:17-cv-01393-SEB-DLP, 2020 WL 1317444 (S.D. Ind. Mar. 20, 2020).

3. *Clark v. Djukic*, No. 2:14-CV-160, 2017 WL 4278039 (N.D. Ind. Sept. 25, 2017).

4. *Cook v. Olathe Medical Center*, 773 F. Supp. 2d 990 (D. Kan. 2011).

5. *Elliot v. Sheriff of Rush County, Ind.*, 686 F. Supp. 2d 840 (S.D. Ind. 2010).

6. *Favela v. City of Las Cruces*, 398 F. Supp. 3d 858 (D.N.M. 2019).

7. *Gold v. City of Sandusky*, No. 3:15-CV-2001, 2018 WL 1468992 (N.D. Ohio Mar. 26, 2018).

8. *Hernandez v. Banner Boswell Medical Center*, No. CV 16-04238-PHX-GMS (ESW), 2018 WL 9918123 (D. Ariz. Aug. 16, 2018).

9. *Hooper v. Pearson*, No. 2:08-CV-871, 2010 WL 2990809 (D. Utah July 26, 2010).

10. *Hunter v. South Dakota Dept. of Social Services*, 377 F. Supp 3d. 964 (D.S.D 2019).

11. *Hyatt v. Falcon*, No. 19-12967, 2020 WL 5605748 (E.D. La. July 16, 2020).

12. *Lockard v. City of Lawrenceburg, Ind.,* 815 F. Supp. 2d 1034 (S.D. Ind. 2011).

13. *Powell v. City of Ocean City,* No. 14-4395, 2016 WL 5417189 (D.N.J Sept. 28, 2016)

14. *Pratt v. Carroll*, No. CV-13-01605-PHX-GMS (MEA), 2015 WL 363283 (D. Ariz. Jan. 27, 2015).

15. *Riis v. Shaver*, No. 3:17-CV-03017-RAL, 2020 WL 3394 (D.S.D. Apr. 28, 2020).

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Obstacles to Timely Decision-Making for Unrepresented Critical Care Patients Without Capacity and Associated Staff Moral Distress: A Single-Center Quality Improvement Study

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ABSTRACT: Background: Incapacitated patients without surrogates are a highly vulnerable population that pose a unique challenge in the critical care setting. Laws regarding consent in this population vary, with many states requiring a lengthy guardian appointment process. Lack of familiarity with local laws and ambiguity with hospital policy can contribute to staff moral distress and exacerbate delays in patient care. Methods: A single-center interdisciplinary focus group was conducted to characterize staff opinions and workflow in the guardianship petition process. Subsequently, a survey was disseminated to various members of the ICU care team. The survey captured demographic information, familiarity with certain aspects of the guardianship process, opinions of appropriateness of care of these patients, and overall feelings of moral distress. Results: Focus group themes included administrative processes, desire for more education, and ethical concerns. Survey results show that clinical staff were largely unfamiliar with both hospital policies (50%) and local legislation surrounding legal guardianship (68%). There was a strong desire for an institutional procedural flowchart (85%). Perception on care varied but had no correlation to demographic factors. Every respondent reported moral distress, ranging from mild to severe (100%). Moral distress was correlated with perception of care (p=0.015), but not demographic factors. Conclusion: An institutional flowchart and other educational materials were developed with the primary intention of alleviating staff moral distress. Secondarily, these educational materials are also intended to improve delays in initiation of the guardianship process as even marginally improving the timeliness of care for vulnerable patients is worthwhile. Continued careful attention to institutional processes can be a manner of upholding the ethical pillar of justice for highly vulnerable individuals.

KEYWORDS: Legal Guardianship; Consent; Critical Care; Surrogate Decision Making; Vulnerability

Introduction

The American Thoracic Society/American Geriatrics Society (ATS/AGS) published a policy statement in 2020 that proposes five ethical goals and six recommendations to navigate medical treatment decisions for unrepresented patients in the ICU. Looking more closely at these goals, we can see basic ethical standards such as protecting and respecting our vulnerable patients, providing adequate medical care, and awareness of discrimination and conflicts of interest.[1] The ATS and AGS recommend a proactive, preventive approach wherein advanced care planning for high-risk patients is offered. They also recommend a thorough search for family members. This policy statement also supports the idea of a multidisciplinary committee making decisions for the patient. However, adherence to these policy recommendations is complicated by heterogeneity within code of law. In 37 states and the District of Columbia, a court-appointed guardian is required to make decisions for this patient population. While 14 states and territories specify out-of-court processes for obtaining consent in unrepresented patients, only 4 dictate use of a multidisciplinary group composed of an ethics committee and the attending physician.[2] These legal requirements bring about questions of guideline feasibility and effectiveness, so the policy statement's recommendations warrant further discussion. The District of Columbia serves as an interesting case study since the area is divided among three different legal jurisdictions, and attending physicians are bound by laws and processes for the jurisdiction of patient residence rather than hospital location.[3]

Unrepresented patients, defined as those who have neither an advance directive nor a surrogate decision maker, account for up to 16% of ICU deaths.[1,4] These patients are some of the most vulnerable, and they often come from marginalized populations such as individuals with substance use disorders, individuals with mental illness or who are unhoused, and socially isolated individuals such as elderly adults.[5] These patients, unable to act autonomously and lacking capacity, exhibit an extreme degree of vulnerability. As highlighted in the 2008 UNESCO declaration of Bioethics and Human Rights and later explored in 2009, special attention and consideration to vulnerable individuals warrants greater emphasis.[6]

Persistent challenges in obtaining consent for medical treatment on behalf of these individuals brings questions about ethics and patients' rights. They also expose these highly vulnerable patients to increased risk. First, there is risk of undertreating the patient by unilaterally withholding or withdrawing treatment. Second, there is risk of delaying treatment while waiting for the court-appointed guardian, which can take up to fourteen weeks in the District of Columbia in some cases.[7] Finally, there is risk of overtreating the patient by offering treatments that may be considered futile under normal circumstances because the clinician is erring on the side of prolonging life. In addition, because there is no one to authorize discharge or transition to comfort care, unrepresented patients often experience extended hospital stays. Based on numerous consults placed to the institutional Ethics Consult service, it became clear that staff in a District of Columbia center found caring for these patients distressing.

Unfortunately, management of care may not necessarily be considered with the same degree of scrutiny in this population. This is not a deliberate neglect, rather a result of bureaucratic obstacles to timely care combined with an absence of family or loved ones' advocacy. It is exactly for this reason - that these individuals exist without any earthly advocates - that we must independently scrutinize our practices and pursue improvement. To investigate institutional factors that may contribute to staff distress and failure to meet the ATS and AGS guidelines for recommended care, a single center exploratory focus group was conducted. It was hypothesized that clinicians would find unrepresented patients morally distressing, be unfamiliar with local laws and hospital policy, and feel that legal delays would be the most significant barrier to timely care. Following the discussion, an ad-hoc survey was disseminated to all individuals associated with the critical care unit to gather opinions regarding care provided to these patients and team member feelings of moral distress. It was hypothesized that clinical workers would experience more moral distress than non-clinical workers. Based on a proposed association between moral distress and decision-making authority, it was hypothesized that clinical workers with more decision making-authority would experience a lesser degree of moral distress.[8] Finally interest in an institutional policy flowchart was also quantified, with the expectation that it would be greatly desired.

Methods

This two-part interdisciplinary quality improvement study involves a focus group and a single-center departmental survey.

<u>Focus Group:</u> Professionals working in a MedStar Georgetown University Hospital (MGUH) ICU that cared for at least one unrepresented patient in the five years, including physicians, nurses, social workers, and lawyers, were recruited via department-wide email. Participant enrollment was tracked, and efforts were made to increase representation from specific personnel groups. The final participants in the focus group included three physicians, one physician assistant, one nurse, two social workers, and one attorney. All enrolled participants attended a focus group via a secure video conference on Microsoft Teams. The meeting began with a brief orientation to the ATS/AGS guidelines for care of the subject population. The group was conducted in an open, conversational manner. One physician participant left the meeting shortly before the conclusion due to clinical responsibilities. Discussion transcript was reviewed by authors FF and CS following the focus group. Based on the discussion content, an ad-hoc post-discussion survey was constructed. Additionally, a qualitative, thematic analysis was conducted by extracting salient quotes and coding by theme.

<u>Survey:</u> Following the needs assessment discussion, the authors created a survey to capture data that could characterize departmental opinions and needs. As the survey met criteria for a quality improvement initiative, it was exempt from IRB approval. A survey was designed in Microsoft Forms and disseminated via email to clinicians working in the ICU, including physicians, physician associates, nurse practitioners, nurses, residents, social workers, and risk management. Informed consent was implied by submitting the form. The survey was initially disseminated to 110 people, among them nurse educators who independently shared the survey. Therefore, total individuals reached is unknown, but the maximum possible response rate was 45.5% based on the known minimum. Survey data were captured anonymously. As this investigation was conducted as a pilot study intended to capture opinions within one institutional department rather than to extrapolate opinions across a population, no assessment of power was conducted prior to survey dissemination. Survey questions included professional role, years at MGUH, number of incapacitated unrepresented patients per year, familiarity with the guardianship petition process, familiarity with DC laws, and degree of moral distress on a scale. The moral distress assessment scale was a simplified version of the Moral Distress Thermometer from the methods of Gianneta et al. and listed five options ranging from no distress to extremely distressed.[9] A copy of the survey is available upon request.

The data were analyzed in Stata (Version 19). The expected cell count was calculated for each row to determine appropriateness of chi-squared vs. Fisher's exact test. Due to small sample size, Fisher's exact test was used as the test of independence. Analysis was conducted with “role”, “years at MGUH”, and “patients per year” as independent variables compared against the question responses. “Opinion on care” was calculated against “moral distress” to assess for validity of survey data, as a relationship between the two is expected to be significant based on definitions. The p-values were calculated and extracted.

Results

Focus Group: Thematic analysis of the conversation highlighted in-hospital processes, legal processes, and ethical challenges with this population. The most frequently expressed individual ideas included the belief that the court guardianship process was the major source of delays in care, a lack of familiarity with local laws and policies, a strong desire for further education on these issues, and feeling that a “one size fits all” solution was not feasible.

During discussion of in-hospital processes, there was a quick consensus that the multi-week legal process by which guardians are appointed is the most significant delay to care. Social workers clarified their timeline to initiate a thorough family search, which moves on a case-by-case basis but operates in the span of days. One social worker pointed out that the process of identifying an appropriate surrogate happens relatively quickly, “within 24 hours” according to her experience. Interviewers inquired about the utility of an institutional flowchart, and group members expressed interest. Other relevant topics falling under this theme were mentioned however with less emphasis and expansive discussion. Specifically, participants also mentioned incomplete information with patient transfer, difficulty obtaining outside facility documentation, and difficulty locating relevant in-house forms. Lack of familiarity with DC laws was mentioned repeatedly by both physician and nurse participants. Legal counsel added that regional laws can leave some degree of ambiguity as to the appropriate course of action rather than offer solutions. In the same theme, two participants mentioned difficulty in identifying preferences based on already documented advanced directive. A desire for more legal education was also repeatedly expressed. One physician participant noted frustration with ambiguous legal timelines. Further orientation to social work utilization and workflow was also mentioned. It was discussed that ICU resident didactics could be a relevant format for these materials. Legal counsel was very amenable to participating in education.

Conversation surrounding ethical issues with this population focused on provision of emergent versus non-emergent standard of care and the importance of surrogacy. Participants agreed that the laws and ethics were straightforward regarding the need for surrogates outside of emergent situations. Specific conversation centered around tracheostomy and gastrostomy tube placement, which are standard procedures for consentable patients but cannot be performed without surrogate consent for unrepresented patients. Participants also discussed the ability of physicians to independently make decisions in the best interest of such patients.

Survey: Survey results were illustrated as below, with participant information highlighted in **Table 1**, familiarity in **Table 2**, and opinions in **Table 3**.

TABLE 1: Characteristics of Survey Respondents

Role		Years Working at MGUH (%)				Patients/Year (%)		
	N=	<1	1 - 5	5 - 10	>10	0-5	6-10	>10
Attendings	10	1 (10)	5 (50)	2 (20)	2 (20)	5 (50)	3 (30)	2 (20)
Residents	8	1 (12.5)	6 (75)	1 (12.5)	0 (0)	3 (37.5)	1 (12.5)	4 (50)
APP	10	0 (0)	4 (40)	2 (20)	4 (40)	3 (30)	5 (50)	2 (20)
RNs	17	0 (0)	8 (47)	4 (23.5)	5 (29.5)	9 (52.9)	1 (5.9)	7 (41.2)
Non-Clinical	5	1 (20)	1 (20)	0 (0)	3 (60)	2 (40)	0 (0)	3 (60)
Total	50	3 (6)	24 (48)	9 (18)	14 (28)	22 (44)	10 (20)	18 (36)

TABLE 2: Familiarity with MGUH guardianship petition process, DC laws surrounding surrogacy, and opinion on utility of a flow chart, shown by staff role.

Role		**Familiar with Petition Process? (%)**		**Familiar with Legislation? (%)**		**Would a Flowchart be Useful? (%)**	
	N=	Y	N	Y	N	Y	N
Attendings	10	6 (60)	4 (40)	3 (30)	7 (70)	10 (100)	0 (0)
Residents	8	3 (37.5)	5 (62.5)	2(25)	6 (75)	8 (100)	0 (0)
APP	10	4 (40)	6 (60)	2 (20)	8 (80)	7 (70)	3 (30)
RNs	17	9 (52.9)	8 (47)	5 (29.5)	12 (70.5)	14 (82.3)	3 (17.7)
Non-Clinical	5	3 (60)	2 (40)	4 (80)	1 (20)	3 (60)	2 (40)
Total	50	25 (50)	25 (50)	16 (32)	34 (68)	42 (84)	8 (16)

TABLE 3: Frequency of responses for different opinions on care received by incapacitated, unrepresented patients and degree of moral distress associated with provision of care for this population.

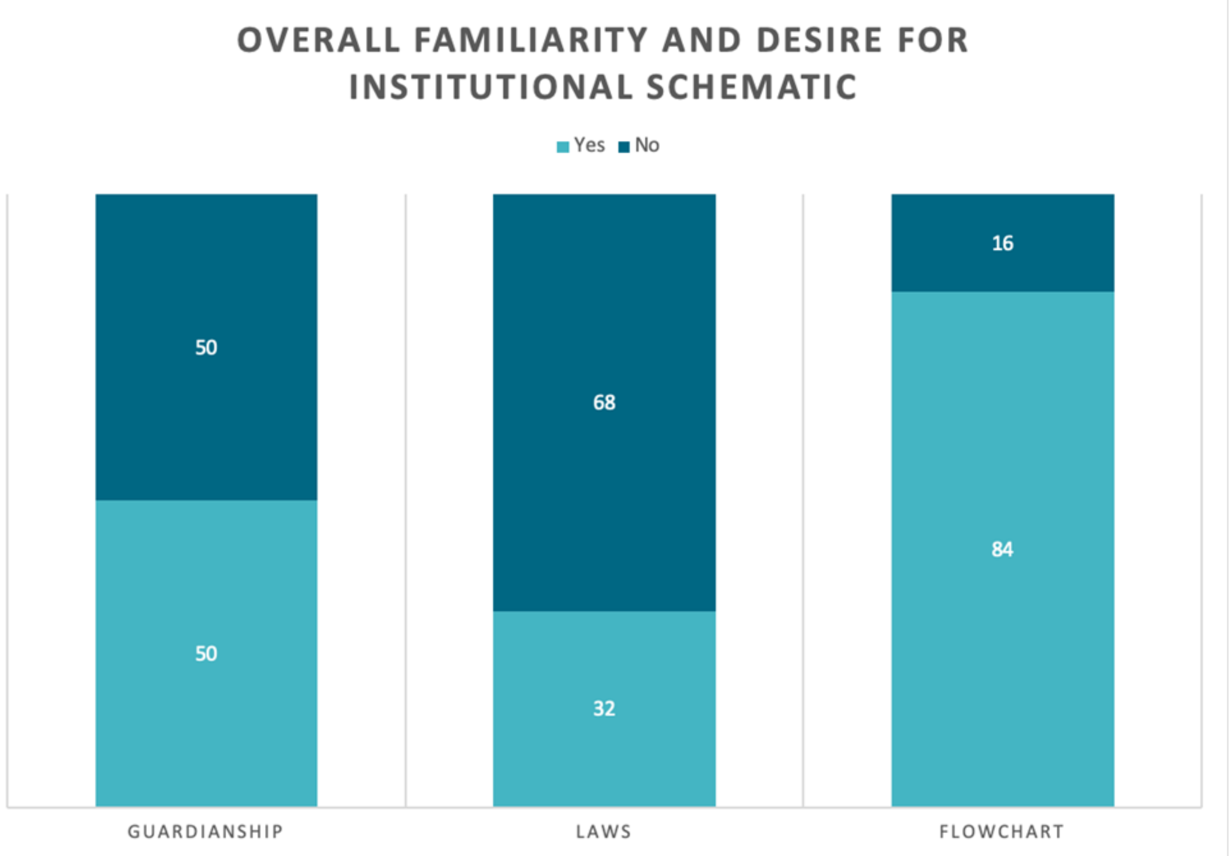
Role		**Opinion on Care Received (%)**				**Degree of Moral Distress (%)**				
	N=	Standard	Undertreated	Overtreated	Depends	None	Mild	Moderate	Severe	Extreme
Attendings	10	5 (50)	0 (0)	2 (20)	3 (30)	0 (0)	2 (20)	5 (50)	3 (30)	0 (0)
Residents	8	0 (0)	1 (12.5)	3 (37.5)	4 (50)	0 (0)	0 (0)	6 (75)	2 (25)	0 (0)
APP	10	4 (40)	0 (0)	2 (20)	4 (40)	0 (0)	4 (40)	5 (50)	1 (10)	0 (0)
RNs	17	6 (35.3)	2 (11.8)	6 (35.3)	3 (17.6)	0 (0)	4 (23.5)	8 (47)	5 (29.5)	0 (0)
Non-Clinical	5	5 (100)	0 (0)	0 (0)	0 (0)	0 (0)	3 (60)	1 (20)	1 (20)	0 (0)
Total	50	20 (40)	3 (6)	13 (26)	14 (28)	0 (0)	13 (26)	25 (50)	12 (24)	0 (0)

Overall, respondents were predominantly clinical staff, with a nearly even split of RN and MD respondents. There were slightly fewer APP respondents. A majority of staff worked between one to five years at MGUH (48%), or greater than 10 years at MGUH (28%). These responses reflect a relatively diverse sample of departmental workers, although only five respondents were non-clinical staff and none were risk management. A majority of respondents had between 0-5 of these patients per year (44%), with only one respondent having 0 in the last year. Otherwise, 36% of respondents reported caring for more than 10 of these patients per year.

Respondent familiarity with the guardianship petition process, familiarity with local legislation, and desire for an institutional flow chart were quantified. Between all respondents, 50% were familiar with the petition process, with a relatively even division within each respondent group ranging from 53%/47% to 37.5%/62.5%. Familiarity with local legislation was markedly different between non-clinical and clinical staff. Overall familiarity was low at 32%. Clinical workers varied from 20%-30% familiarity and 80% of non-clinical workers indicated familiarity. A majority of respondents felt that a flow chart would be useful (84%), with 100% of MDs feeling it would be useful, and 60% of non-clinical staff feeling it would be useful. This likely reflects the different responsibilities and educational background of these groups. Of clinical staff, nurses and mid-level providers indicated perceived utility with a rate of 70%-80%.

Overall, the individuals surveyed expressed a variety of opinions regarding the care of these patients. Forty percent felt that care provided was standard, and only 6% of this group felt that patients were undertreated. This was surprising, as it was initially expected that more staff would feel that these patients are undertreated due to guardianship petition-associated delays in care. However, 28% felt that standard of care depended on the individual case, which could capture more instances of undertreatment. There were more opinions expressing a sense of overtreatment (26%) than initially expected. However, due to the need for a surrogate to consent to withdraw care or to transition to comfort care only, it serves to reason that a significant proportion of patients are overtreated until a legal representative can consent to these plans. Interestingly, 0% of attending physicians felt that these patients were undertreated and 50% felt that care was standard, whereas 12.5% of residents felt that patients were undertreated and 0% felt that care was standard. The difference in perception of undertreatment and standard of care is interesting and may reflect attending familiarity with current guidelines, policies, and processes. This famili-

FIGURE 1: Visualization of overall familiarity with petition process, laws, and opinion on flowchart utility. Most respondents are unfamiliar with laws and think that an institution flowchart would be useful in the management of these patients' care.

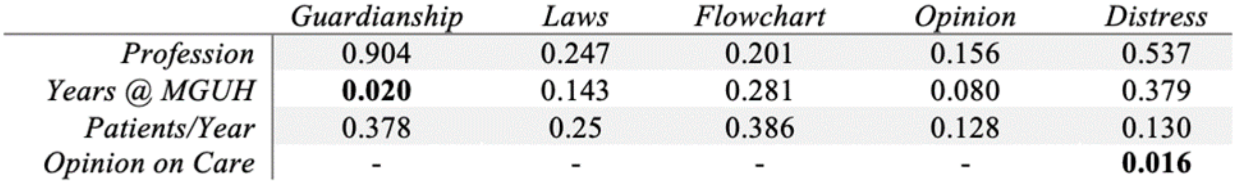


arity typically develops with time and exposure. This opinion could also be attributed to the attending physicians' role in finalizing care plans.

Regarding degree of moral distress, it was most notable that neither the option indicating no moral distress nor extreme moral distress were selected by any participant. There was a normal distribution of selected responses for this category, with 50% of participants indicating moderate moral distress, and 26% and 24% indicating mild and severe distress, respectively. This overall distribution of mild, moderate, and severe was similar between physicians (20%/50%/30%) and nurses (23.5%/47%/29.5%). Residents overall indicated higher degrees of moral distress, with 0% selecting mild, 75% selecting moderate, and 25% selecting severe. This difference in moral distress between groups of different authority levels is supported by the literature, however it was surprising that other groups with less decision-making power, such as nurses, did not have higher levels of moral distress.8,10 Non-clinical staff felt the least degrees of moral distress, with 60% indicating mild, 20% indicating moderate, and 20% indicating severe. This skew towards lesser moral distress was expected based on less direct patient exposure, however it was surprising to see that 20% indicated severe distress. The association between care team role and moral distress was calculated and was not found to be statistically significant (p=0.537), which was surprising considering the literature associating decision making power with moral distress. However, this study was not adequately powered to capture a population level phenomenon and reflects the opinions only amongst the care team in a single department.

The association between years at MGUH and impression of care received neared statistical significance but fell slightly short (p=0.080). There was no significant association between the number of patients treated per year and perception of care (p= 0.128). A strong correlation existed between opinion on care and moral distress (p=0.016), which is expected based on the definition of moral distress and supports validity of the survey results **(Table 4)**.

TABLE 4: Total survey participant association between profession, years at MGUH, and patients per year compared against familiarity, flowchart utility, care opinion, and degree of moral distress.

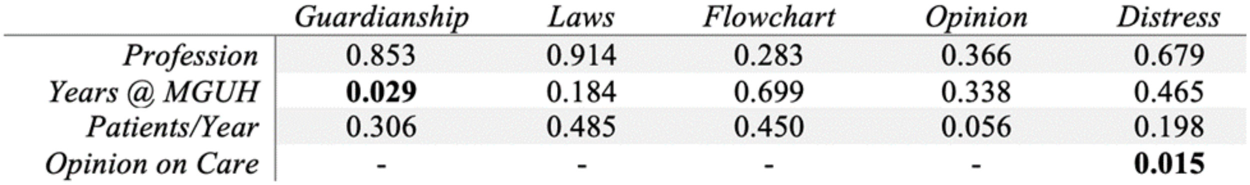


	Guardianship	*Laws*	*Flowchart*	*Opinion*	*Distress*
Profession	0.904	0.247	0.201	0.156	0.537
Years @ MGUH	**0.020**	0.143	0.281	0.080	0.379
Patients/Year	0.378	0.25	0.386	0.128	0.130
Opinion on Care	-	-	-	-	**0.016**

The association between years at MGUH and impression of care received neared statistical significance but fell slightly short (p=0.080). There was no significant association between the number of patients treated per year and perception of care (p= 0.128). A strong correlation existed between opinion on care and moral distress (p=0.016), which is expected based on the definition of moral distress and supports validity of the survey results.

Because non-clinical workers and clinical workers vary so greatly in their daily workflow and relation to these patients, the responses of clinical workers were separately analyzed **(TABLE 5)**. Excluding the non-clinical workers yielded largely similar results, except in one category. Specifically, there was a nearly significant association between the number of patients per year and the opinion on the care provided (p=0.056). This likely captures another facet of experience shaping opinion. People with more patients per year are expected to be more familiar with the typical pattern of care that these patients receive. As above, opinion on care influenced the degree of moral distress, with no major difference (p=0.015).

TABLE 5: Clinical respondents analyzed separately for association between profession, years at MGUH, and patients per year compared against familiarity, flowchart utility, care opinion, and degree of moral distress.



	Guardianship	*Laws*	*Flowchart*	*Opinion*	*Distress*
Profession	0.853	0.914	0.283	0.366	0.679
Years @ MGUH	**0.029**	0.184	0.699	0.338	0.465
Patients/Year	0.306	0.485	0.450	0.056	0.198
Opinion on Care	-	-	-	-	**0.015**

Discussion

Provision of informed consent is a core tenant of modern medical ethics. In emergency situations, code of law dictates that life-saving decisions are made without consent and err in favor of preserving life.[11] Patients in emergencies are often rendered unable to make informed decisions and thus it is morally permissible to act without consent under the assumption that consent is implied. However, outside of an emergent threat to life or limb, physicians are not generally permitted to make more permanent decisions for their patients. This norm brings both positives and negatives to complex care. On the positive side, it protects patients from competing interests and varying personal beliefs. This conflict was voiced by one participant who stated, “It's hard to not have your own personal beliefs come into [play] when you're making these decisions towards a more permanent care plan.” This underlies the crux of why physicians, specifically individual physicians, are not permitted to make unilateral decisions. Physicians balance a group of competing interests and may be torn between the needs of other patients, the needs of their colleagues, and the needs of the hospital. This in and of itself is not necessarily problematic, as stewardship of resources is a necessary aspect of the position. However, this highlights exactly the need for a patient guardian to participate in decision making. When many factors all compete for priority, there ought to be one person present in the conversation who speaks only for the individual. Without this presence, the vulnerable are left voiceless and are more easily overlooked.

Unfortunately, this rule intended to emphasize the best interest of vulnerable individuals has a double effect, one which is particularly noteworthy in our population of interest. Once outside emergency care ends, physicians are unable to advance care plans for patients without surrogate consent. For example, critical care physician would be unable to perform a tracheostomy on an unrepresented patient because this falls outside the purview of emergency care although it may be in the patient's best interest. Through this imposed delay in provision of appropriate care, physicians are subjected to moral distress. In states with two physician consent for this population, this could be feasible. However, states requiring guardianship appointment have unintentionally imposed a multi-week wait time in an attempt to protect these patients. Patients remain in a holding pattern which is against their best interest and may remain in intensive care for a prolonged period. Physicians and other staff find this situation frustrating as they find their actions limited. As noted by one focus group participant when discussing the guardianship process, "it's painful. It takes time."

Moral Distress and Proposed Intervention

These patient care scenarios, in which providing standard of care is hindered by the legal process, are a classic example of situations that evoke moral distress. Indeed, this quality improvement investigation is the result of discussion with a morally distressed provider. Survey results show that employees at all levels and roles experience some degree of moral distress.

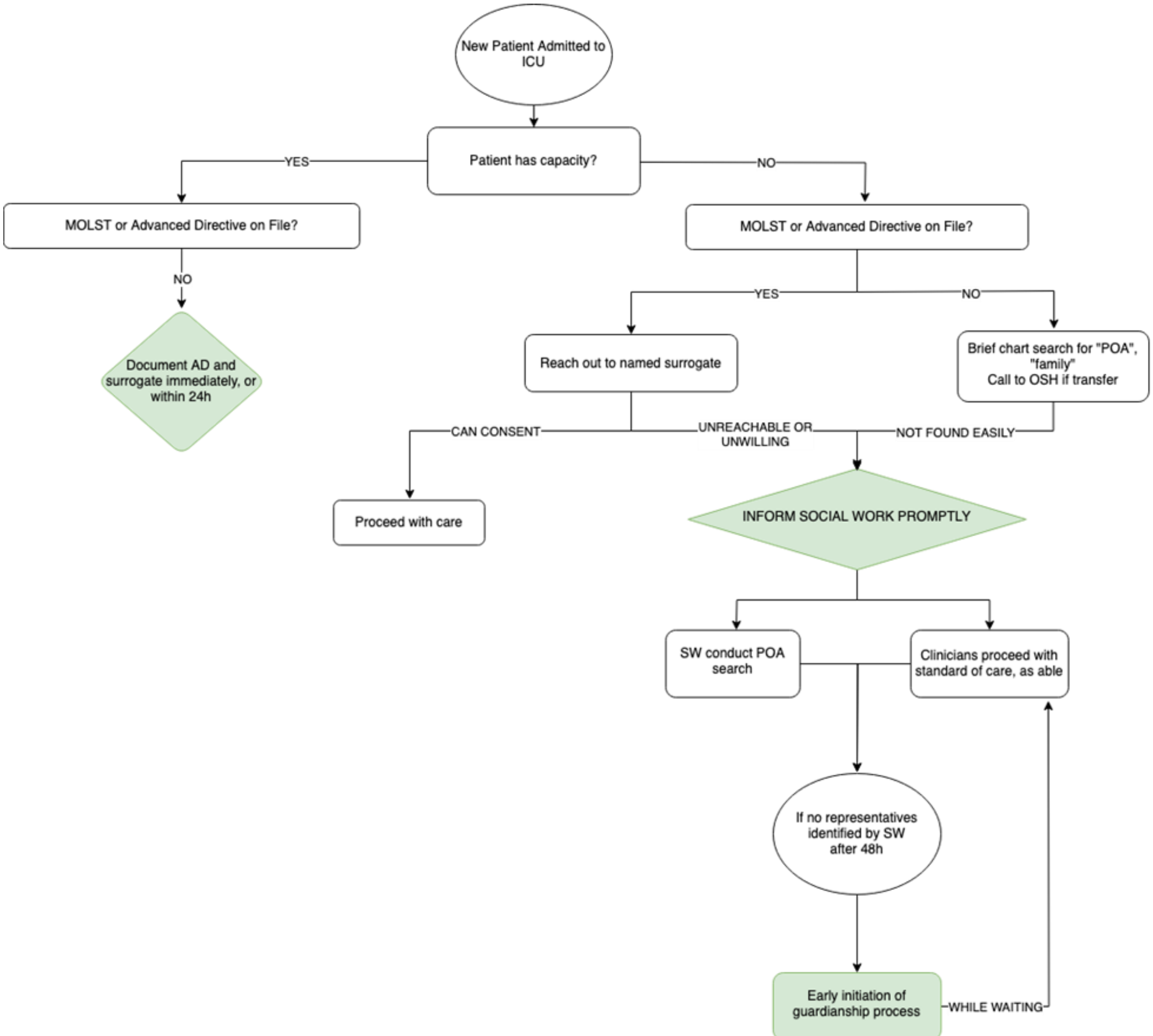
Care for unrepresented patients is likely to evoke moral distress for several reasons. Most significantly, physicians are unable to advance care plans for their patients. Whether the individual physician feels that placement of a tracheostomy and gastrostomy tube is in the patient's best interest or that transition to comfort care would be more appropriate, no action can be taken. The patient's best interest is to progress in one direction or the other, and the physician cannot facilitate that. Therefore, the physician is caught in a position of being unable to act on their moral duty to the patient. Secondly, it is possible that the act of discussion with a surrogate acts to distribute moral burden and shift it from falling solely on the physician. The act of "debriefing," or having an intentional discussion following a morally injurious patient encounter, has been explored as an intervention protective against moral distress.[12] While discussing patient status with surrogate requires more mental energy than a true debrief would, it allows for the physician to express opinions and to even act as an advocate helping to guide the surrogate to the appropriate outcome. In these care situations without a surrogate, we then see how much moral responsibility falls solely on the attending physician. Understanding better the potential sources of moral distress brings to mind the question of next steps.

A straightforward approach to mitigating moral distress in ICU staff is intervening upstream when a patient is at risk for requiring legal guardianship. This is also in accordance with the ATS/AGT policy statement, which recommends a preventative approach.[1] Prior quality improvement research for this population has identified several factors that prolong hospital stays in these patients, including inadequate mechanisms for identifying at-risk patients, and role ambiguity and varying expertise among social workers.[13] The most obvious solution to preventing these patient care scenarios increase rates of documented advanced directives. For example, a policy of documenting preferred patient surrogate and advanced directive immediately upon ICU admission could be helpful. This will not address patients who are transferred or admitted already incapacitated, however it could pre-empt a portion of patients from becoming both unrepresented and incapacitated. For patients being transferred, specifically noting surrogate contact information and advanced directive in transfer documents could prevent a number of these cases. While national efforts to increase advanced directive documentation in the seriously chronically ill have been unsuccessful, perhaps engaging in these efforts in a critical care setting will be more fruitful.[14] Unfortunately, as discussed in the focus group, "…it's really hard to apply a sort of formulaic training to these individual, really nuanced, really complicated feeling situations."

As elimination of these troubling scenarios is not entirely feasible, other strategies to mitigate moral distress in ICU workers are warranted. Knowing that moral distress is associated with burnout and psychiatric symptoms of PTSD, depression, and anxiety, the institution ought to take measures to support staff.[10] In accordance with the Quadruple Aim of healthcare management, well-being of the healthcare team is a pillar of healthcare delivery. Strong leadership support is shown to mitigate moral distress, however the literature shows that education based interventions are more effective.[15] The focus group echoed interest in a flow chart, with one participant describing the idea as "very helpful, and I think it might help to give confidence in the steps of the process and also to … move things along." Thus, we created educational materials that aim to not only improve time to activation of the guardianship process, but also to mitigate the moral distress that these cases cause.

Below is the flowchart designed with several rounds of interdisciplinary input. Policy documentation and other educational materials are included but may be institution specific.

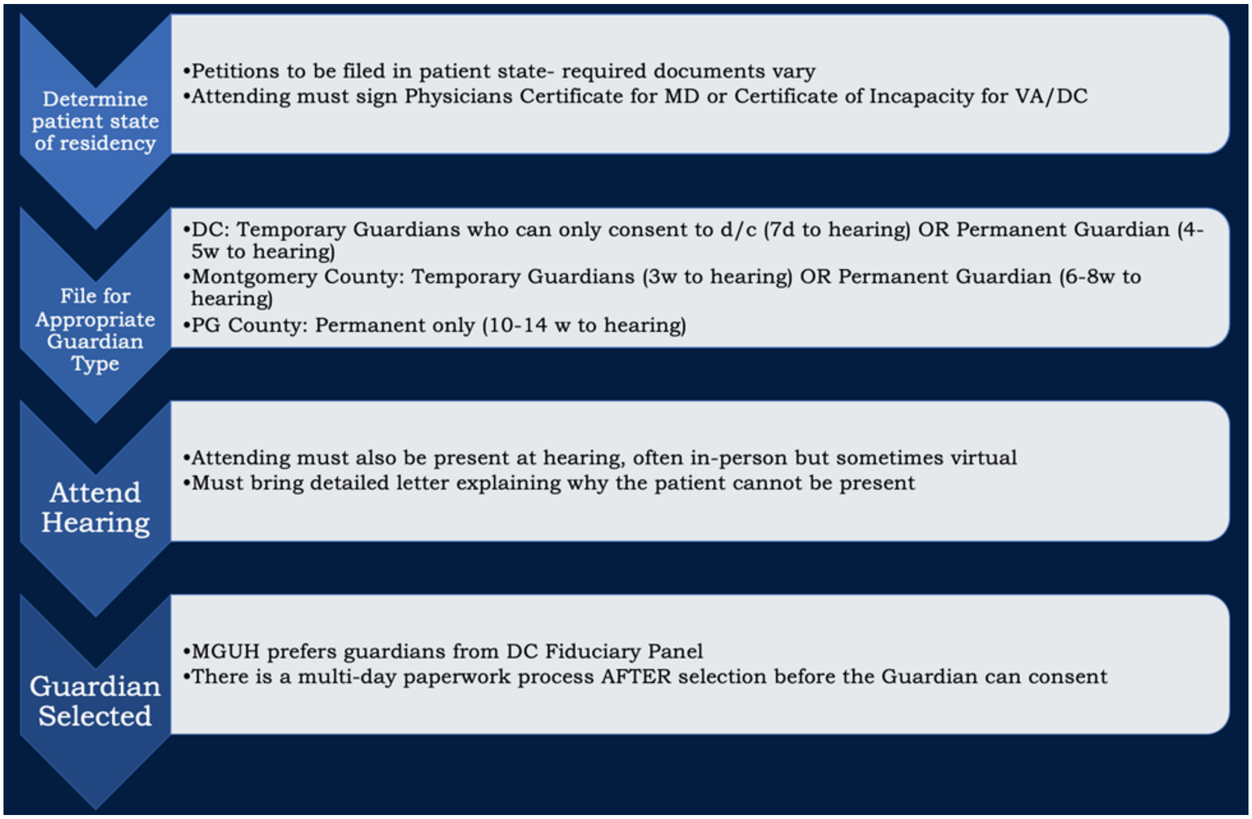
FIGURE 2: An institutional flowchart showing an overview of the guardianship process. Steps highlighted in green illustrate historic areas of delay. These steps' timelines are more clearly defined with the intention of improving delays.



Education Materials for Clinical Staff and Flow Chart

MedStar Health is comprised of hospitals and outpatient sites in three distinct areas - Maryland, Virginia, and the District of Columbia. Each jurisdiction has different laws regarding surrogate care. Practicing in this region is particularly complex as physicians are responsible for following the laws corresponding to area of patient domicile rather than hospital location. Therefore, educational materials may be especially useful to clarify processes for DC MedStar clinicians who must follow multiple different sets of laws and processes. One participant expressed that "[t]he laws are very different and we are applying things differently at different MedStar hospitals and so it would be helpful to understand if this is just different [that] there's different practice patterns by hospitals and what the actual legal standard is in each area as we're trying to make these decisions." The survey results indicating that 100% of physicians desired a flowchart outlining their role in the process further illustrates interest from practitioners in this group. Also, better orientation to hospital policy can clarify roles and timelines which may alleviate some staff frustration. Unnecessary delays can be avoided if team members know how quickly to initiate the guardianship process, and necessary delays will be less frustrating if team members understand the process. In fact, an educational approach is a previously validated intervention. A prior quality improvement initiative that clearly outlined an institutional guardianship process saw not only intangible changes such as improved team communication but also length of stay reduction.[13] The educational materials in our investigation are different as they address the critical care setting- one not included in the prior work. Our materials also focus more closely on timeline and delineation of role and contain relevant legal information for the three-territory area.

FIGURE 3: An illustrative diagram aimed at physician care team members. This graph clarifies attending-specific duties in the process and provides timeline estimates. Regional differences in law and timeline are displayed.



- Petitions to be filed in patient state- required documents vary
- Attending must sign Physicians Certificate for MD or Certificate of Incapacity for VA/DC

- DC: Temporary Guardians who can only consent to d/c (7d to hearing) OR Permanent Guardian (4-5w to hearing)
- Montgomery County: Temporary Guardians (3w to hearing) OR Permanent Guardian (6-8w to hearing)
- PG County: Permanent only (10-14 w to hearing)

- Attending must also be present at hearing, often in-person but sometimes virtual
- Must bring detailed letter explaining why the patient cannot be present

- MGUH prefers guardians from DC Fiduciary Panel
- There is a multi-day paperwork process AFTER selection before the Guardian can consent

Conclusion

This investigation was initially undertaken in response to several ethics consultations for incapacitated unrepresented patients who were unable to be consented for a tracheostomy as consistent with the standard of care. The results of this work revealed a gap in staff education on laws and policies, so an institutional flow chart and other educational materials were created. Next steps include dissemination of these materials in a way that is easily accessible. Based on the strong interest for education, development of a didactics session warrants further discussion. For such a session, both social workers and legal counsel offered to educate critical care staff on these cases. A brief educational presentation including the social work workflow, orientation on legal process, and impressions from ethics consultants may be useful. Focusing on the primary aim of alleviating moral distress, quantification of moral distress following an educational intervention is a long term project of interest. Regarding other feasible institutional interventions, we conclude that it is best to focus on upstream factors to avoid these situations arising, as is in line with the AST policy document. Based on the risks associated with a patient becoming incapacitated without representation, the effort is worthwhile. Beyond being simply worthwhile, attempts to improve delays in care for this highly vulnerable population is a matter of justice.

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“Give Her What She Wants:” An Ethical Exploration of Factitious Illness and Disagreement Between Inpatient and Outpatient Providers

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ABSTRACT: This article presents a challenging case encountered by a hospitalist admitting a young woman with a complex medical history, including a rare autoimmune disease and anaphylactic reactions to medications. Safety concerns arise from the patient's outpatient medication regimen. The discovery of a history involving factitious disorder and self-injury adds uncertainty to the patient's diagnosis and treatment. The commentary delves into the significant ethical challenges surrounding uncertainties in diagnosis and treatment legitimacy, the doctor-patient relationship, and collaboration between inpatient and outpatient providers. Emphasizing the need to recognize limitations and uncertainties, the article highlights the importance of considering diverse perspectives in making ethical decisions for the well-being of the patient.

KEYWORDS: Factitious Illness; Patient Safety; Clinical Disagreement; Physician-Patient Relationship

Case Presentation

A 24-year-old woman with a complex medical history is presenting for hospital admission at an academic medical center. She reports a rare autoimmune disease, anaphylactic reactions to numerous common medications, and an inability to tolerate food by mouth. She receives total parental nutrition (TPN) through an intravenous catheter and her medications through a gastric tube. Her outpatient medication list includes high doses of corticosteroids, opiates, and sedatives. The combination and dosages of these medications raises safety concerns for the admitting hospitalist. Her medications are prescribed by an immunologist from another hospital network who has seen the patient regularly in the outpatient setting for the last several years.

The patient presents with a fever and concern for infection two weeks following discharge for a similar matter. During her prior hospitalization, she received a course of antibiotics, and her outpatient medication regimen was continued without alteration. During the initial evaluation for this admission, she requests her home medications be continued with increased dosages of intravenous pain medication, diphenhydramine, and benzodiazepines.

An examination of the electronic health record uncovers a detailed care plan from her immunologist’s hospital, outlining a history of factitious disorder and self-injury. Repeated laboratory testing for the suspected autoimmune disorder have yielded negative results and her previous instances of anaphylaxis have not been substantiated. Furthermore, observations indicate that she can ingest food orally. This raises concerns about whether she may actually require total parenteral nutrition, a gastric tube, or the medications she is prescribed.

Recognizing the need for action, the hospitalist contacts her outpatient immunologist to discuss the potential for factitious disorder and to review the safety of her medication regimen. The immunologist, familiar with the patient’s history, opposes the hospitalist’s safety concerns. She advocates for an approach centered on accommodating the patient's requests and cultivating a therapeutic relationship, citing that it may enhance health outcomes: “Give her what she wants.”

Commentary

The ethical challenges of this case are multifaceted, presenting the hospitalist with a series of ethical challenges within a context of significant ambiguity. Uncertainty shrouds the authenticity of the patient's autoimmune disease diagnosis and the legitimacy of her medication regimen. The provider must navigate these intricacies when deciding on the best course of action for the patient's complex medication plan. This requires addressing medical uncertainties, navigating the doctor-patient relationship, and fostering collaboration between inpatient and outpatient providers, all while adhering to fundamental ethical principles.

Uncertainty

There are few, if any, certainties in medicine. In this case, the list of uncertainties is considerable. Does this patient have an autoimmune disease? While the testing for the reported autoimmune disease has been negative, we remain unsure if this is *all* factitious. Perhaps her medication regimen has been treating *something*, even if there is uncertainty about *what.*[1] Possibly, the patient has a serious disease for which she has not been tested. There is additional uncertainty about whether the patient has even been taking the medications that she has been prescribed. Administering the full reported doses of immunosuppression, opiates, and sedatives in combination could be life-threatening without patient acclimation. If the patient should not be taking these medications, ought they be discontinued? And, if so, is that safer? Abrupt discontinuation of benzodiazepines and immunosuppression can lead to seizures, adrenal insufficiency, and other complications. It may feel like the hospitalist needs to make decisions with incomplete information and serious risk of harm either way. In this case, a cautious, stepwise approach to gradually tapering and discontinuing potentially harmful medications would be the first and most prudent course of action.

The complexity of this case intensifies with the intertwining of real illness in the backdrop of factitious illness. The patient’s infection is real in the sense that it is biologic and carries diagnostic clarity. The patient has a real fever. Nevertheless, the infection may be iatrogenic, caused by unnecessary immunosuppression. Despite the possibility of self-inflicted harm, it does not diminish the 'reality' of her illness, prompting a deeper examination of what constitutes ‘real’ illness. This raises questions about the nature of factitious disorder and the appropriate treatment strategies. Addressing and preventing further harm requires the hospitalist to navigate a complex ethical landscape, carefully balancing the patient's psychological needs for control, validation, and empathy with their ethical duty to evaluate and treat the infection as well as avoid causing harm.

Our knowledge about the outpatient immunologist and the motivation behind her recommendations is also limited. She could be prescribing this regimen with 'palliative' intent. These agents might be prescribed to alleviate suffering, enhance social or functional aspects of the patient's life, extend the patient's time outside of the hospital, or align with the patient's values. Perhaps the immunologist is promoting beneficence, justice, and patient autonomy. Yet, are the immunologist's intentions relevant, and if so, how much should they factor into the decision? If her prescribing is inadvertently harmful, it still conflicts with the principle of nonmaleficence, necessitating the hospitalist to prioritize the patient’s best interest and make changes to the medication regimen.

This case underscores the importance of recognizing the limitations of our own knowledge and the uncertainties in medicine, while acknowledging the potential for moral distress when we find ourselves inadequately informed to make ethical judgments. Grasping the known, knowable, and unknowable allows for a more profound confrontation with ethical dilemmas.

Relationships

Attempts to define the patient-physician relationship have been made since Hippocrates. In today’s medical landscape, the gold standard for a patient-physician relationship is one that has been built longitudinally and on trust.[2] Primary care doctors, for example, who see patients regularly over an extended period, have traditionally earned high regard. Not long ago, primary care physicians routinely cared for their hospitalized patients, further solidifying the longitudinal nature of their relationships. However, a new trend has emerged in the last thirty years, with patients encountering different physicians in the hospital than in their regular outpatient clinics. Hospitalists are part of this shifting paradigm, bringing forth a vital question: how can two physicians, both responsible for a single patient's care, effectively collaborate?

While collegial and professional peer relationships are important to medical practice, a physician’s primary obligation is to the patient. Additionally, there is legal and ethical precedent for ensuring peers practice thoughtful and safe medicine.[3] In this case, the hospitalist ought to be compelled to taper or discontinue harmful medications. This decision stands firm, irrespective of the outpatient immunologist suggesting a different path or even a looming sense of futility: “If I discontinue a medication now, it will soon be restarted on hospital discharge by the immunologist.” The inpatient provider is not a puppet of the outpatient provider. Instead, hospitalists must rely on their own medical and ethical instincts in crafting optimal treatment strategies.

An acknowledgement of disparate vantage points may also be helpful. Checks, balances, and second opinions push medical care towards safety and better patient outcomes.[4] The hospitalist is seeing the patient at her lowest ebb. Seeing the patient during a medical decompensation may be something only the hospitalist appreciates, whereas seeing the patient while at home, stably tolerating her medications could be something only the outpatient immunologist appreciates. Each watch only half of a two-act play. Both believe that that the patient deserves an optimal treatment plan, even if they would approach treatment differently.

The patient may also find the dynamics of her relationships unclear. With a solid bond with her immunologist and a consistent presence at outpatient appointments, she likely perceives some benefits from the medications and hasn't signaled any doubts about their safety. The patient may already be questioning the trustworthiness of the hospitalist who is voicing concerns that other providers have not. On one hand, a strict boundary setting or medication tapering may further jeopardize their patient-physician alliance. Conversely, the fact that neither a colleague from two weeks ago nor the outpatient provider raised concerns about the regimen does not diminish the hospitalist's obligation to assess its safety. The hospitalist grapples with an ethical tightrope, juggling the dual demands of preserving the patient-physician relationship - navigating concerns and upholding trust - while steadfastly pursuing the patient's well-being. Simultaneously, the patient might sense a shared helplessness, ensnared in a web of conflicting demands without the reins of agency.

Leaning on Nonmaleficence and Transparency in Communication

Physicians are obligated to act in the best interests of every patient and, above all, cause no harm. Within this responsibility, challenging questions arise regarding defining the "best interests" of a patient with a factitious illness.[5] Additionally, it remains unclear what actions would cause "harm" or "benefit" in such cases, especially in the context of established outpatient care and the transient nature of inpatient hospital encounters.

The hospitalist, aware of the potential harm from the outpatient medication plan, has an ethical duty to proceed with a safe reduction of the drugs, guided by medical knowledge and ethical principles, particularly those of beneficence and nonmaleficence. This process requires straightforward communication with the patient and the outpatient doctor to ensure transparency. The hospitalist must address the patient's concerns with direct, honest dialogue and document the reasons for the medication changes for the outpatient provider. Effective communication and collaboration with outpatient providers is crucial, as is addressing the patient's concerns and maintaining trust. This case serves as a reminder that ethical decisions often require a delicate balance of multiple perspectives, acknowledgement of uncertainties, and an unwavering commitment to the patient's well-being.

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