Volume 8
Number 2
May 2022

JOURNAL OF HOSPITAL ETHICS

THE JOHN J. LYNCH, MD CENTER FOR ETHICS

MedStar Health

JOURNAL OF
HOSPITAL ETHICS
THE JOHN J. LYNCH, MD CENTER FOR ETHICS

EDITORIAL GROUP

EDITOR-IN-CHIEF
Evan G. DeRenzo, PhD

MANAGING EDITOR
Christian Carrozzo, PhD (c)

CONTENT EDITORS
Jory Barone, MLS
Fred King, MSLS
S. Layla Heimlich, MSLIS

MEDICAL EDITORS
Jack A. Sava, MD
Michael Pottash, MD

ADMINISTRATIVE ASSISTANT
Nikki Glover

INTERIM EXECUTIVE DIRECTOR
Ben Krohmal, JD

EDITORIAL ADVISORY BOARD

Amanda Anderson, RN, BSN, CCRN
Fellow in Clinical Scholars, Robert Wood Johnson Foundation

Amanda Bush, MA, BSN, RN, CCRN
Regional Nurse Wellness Coach Specialist
MedStar Health, Center for Wellbeing

Chee M. Chan, MD, MPH
Medical Director, Intermediate Care Unit, MedStar Washington

Zacharia Cherian, MD
Chair, Department of Neonatology, MedStar Washington

O. Mary Dwyer, JD, MA
Assistant Professor, Department of Bioethics, Case Western Reserve School of Medicine

J. Hunter Groninger, MD
Director, Section of Palliative Care, MedStar Washington

Laura K. Guidry-Grimes, PhD
Assistant Professor of Medical Humanities and Bioethics, University of Arkansas for Medical Sciences

Josh Hyatt, DSH, MHL, CPHRM
Adjunct Professor, Massachusetts College of Pharmacy & Health Sciences

Jack Kilcullen, MD, JD, MPH
Physician, Medical Critical Care Service, INOVA

Eran Klein, MD, PhD
Assistant Professor, Department of Neurology, Oregon Health & Sciences University

Jason Lesandrini, LPEC
Assistant Vice President of Ethics, WellStar Health System

Barbara M. Mitchell, RN, MSN
Director, Quality Resources & Outcomes, MedStar Washington

Stephen W. Peterson, MD
Physician, Department of Psychiatry, MedStar Washington

Ira Y. Rabin, MD
Vice President of Medical Operations, MedStar Washington

Jack Schwartz, JD
Adjunct Professor and Senior Research Associate, University of Maryland Carey School of Law

Stephen Selinger, MD
Chief Medical Officer, Anne Arundel Medical Center

Eric A. Singer, MD
Assistant Professor, Section of Urologic Cancer, Rutgers Cancer Institute of New Jersey, Robert Wood Johnson Medical School

Carol Taylor, RN, MSN, PhD
Senior Research Scholar, Kennedy Institute of Ethics and Professor, School of Nursing & Health Studies, Georgetown University

MedStar Health

© Copyright 2022 John J. Lynch, MD Center for Ethics. ISSN (Print) 1938-4955, ISSN (Online) 1938-4920. All Rights Reserved.

Volume 8
Number 2
May 2022

JOURNAL OF HOSPITAL ETHICS

THE JOHN J. LYNCH, MD CENTER FOR ETHICS

Rounding with the Editor

Features

In Practice

Program for Neuroethics & Clinical Consciousness

JoHE VOLUME 8, NUMBER 2

ROUNDING WITH THE EDITOR

Communication and Psychiatric Overlay

Evan G. DeRenzo, PhD

Dear Readers,

Welcome to Volume 8, Number 2 of the Journal of Hospital Ethics (JoHE). In this issue we include features and cases that raise a variety of important and complex topics. A topic that is particularly near to my heart is that of our second case analysis on medical respite for those experiencing homelessness. We at the Lynch Center for Ethics are working on a long-term project to bring more medical respite beds to Washington, DC. Important, also, is the topic of assessments of decisional capacity as is the focus of our third case analysis in this issue. Our own Managing Editor, Christian Carrozzo, is co-editing an upcoming volume for Oxford University Press on the topic of mental capacity, and since this is also a long-term project I intend to discuss in the future, I will refrain from delving into the two case analyses provided by the Editorial Group. Doing so nevertheless leaves me with much to discuss.

Jada Wiggleton-Little's work as Visiting Scholar to the Program for Neuroethics and Clinical Consciousness (PNCC) is breathtakingly insightful in envisioning a framework that conjoins the languages of subjective patient explanations of their experiences of pain with how clinicians receive that information. Further, rather than merely leaving us with a new way to think of what is so often identified as a communication mismatch, her strikingly original thinking goes on to provide a path to correcting the communications defect. The suggestion that quite different languages could be merged into one language, a pidgin language of pain, is an intriguing way to think of patient/physician communication. Wiggleton-Little's work is conceptually impressive and, simultaneously, clinically intuitive. I suggest readers interested in this area of medicine read it, and a bit later return to it, so that its highly creative approach to a chronic and serious problem can be fully appreciated (in the broadest sense of the word).

Our first case analysis by Madison S. McCarthy and Thomas A. Bledsoe on the end-stage surgical difficulties after foreign body ingestion also addresses a deeply concerning, albeit infrequently occurring, problem. According to the National Alliance on Mental Illness (NAMI/nami.org) Borderline Personality Disorder (BPD) may be a seriously underdiagnosed mental illness. The NAMI website indicates that there is a 1.4% prevalence in the United States (US) adult population. But it then goes on to suggest that although 75% of the diagnoses are in women, men may be roughly equally afflicted but misdiagnosed as Post-Traumatic Stress Disorder (PTSD) or depression.

This case paints a clear picture of the additionally rare manifestation of foreign body ingestion in patients with BPD. The authors' statistic that in 2014 there were only 15 case reports in the literature although approximately 1500 patients die annually of complications from this rare BPD symptom is telling. By the time such a patient with BPD is out of surgical options, care of such patients has, as the authors point out so convincingly, reached the point that the only reasonable treatment left is palliation unto death.

In more than 20 years at Washington Hospital Center, it has always seemed to me that the most ethically, and often medically, complex patients are those suffering from somatic disease with psychiatric overlay. BPD is arguably one of the most ethically and psychiatrically complex disorders. I have found that it is particularly incredible to residents and fellows that patients can be dying of their psychiatric disease. That psychiatric illness can be terminal or end-stage, aside from the commonly self-inflicted cause of death of suicide, can be perplexing for many clinicians. Yet, that patients can indeed die as a result of their psychiatric disease is what this case so obviously demonstrates. And although learning from an N of one (or 12 or 15) can produce questionable conclusions, this case is beautifully instructive in its starkness.

As to our two excellent features, Lyndsay Semler's report on how the largest hospital system in Oklahoma operationalized a strategy to manage scarce resource allocation if crisis standards of care were to be initiated in their state is highly instructive. Given it appears we might be living with periods of calm interrupted by periods of sharply rising COVID infection rates, disseminating these good strategies is sure to be helpful to others. Moreover, this work helps assure that when others face this problem, whether COVID related or no, they have an ethically sound model to emulate, avoiding having to start from scratch.

One of the most important aspects of this article is that the author, along with many others throughout her hospital system, actually tested their plans. Since the pandemic, many hospitals and hospital systems have designed plans to one degree of completeness or another. It is something else to have actually experimented with the processes that would be put in place if a crisis level of care were to be instituted. Additionally, the Oklahoma plan serves as a blueprint that could be productively replicated in virtually any other similarly organized hospital system.

Finally, I now turn to our second feature, "To Feed or Not to Feed: The Effect of Anorexia Nervosa on Autonomous Decision Making" by Eli Weber and Jo Everett. Like our end stage surgical case, this piece is focused on one of the most serious, difficult to treat, ethically complicated, and generally mystifying psychiatric conditions. The focus here, however, is on Anorexia Nervosa. Anorexia Nervosa entwines serious, sometimes lethal, physical problems with hugely challenging mental illness.

In this article, the authors argue that many patients with Anorexia Nervosa can satisfy the requirements for autonomous decision-making.

The authors explore most interestingly the ethical and potentially morally distressing quandary for clinicians who make the sometimes-fatal choice for those they assess as decisionally capacitated. Further, the potentially profound challenges this choice creates to assumptions about the very foundations of moral medicine, especially when patients die of their disease, is examined with the gravity it deserves.

If compelled nutrition is typically ineffective, given that a risk vs benefit analysis is a standard ethical consideration in medicine, if the risk of harm is tipped beyond the point of potential for benefit, one need go no further.

Regardless of the variation in prevalence estimates across studies, eating disorders are becoming more common,[1, 2] including in Asia and the Middle East.[3] Whether this is a result of increased incidence, or earlier and more frequent diagnoses, is still unclear. What is encouraging, however, about this frustrating medical and psychosocial condition is that treatment approaches are becoming increasingly nuanced for both Anorexia Nervosa and Bulimia Nervosa, albeit that both are notoriously difficult to treat.[4-6] What is most interesting is that current research is paying attention to diversity in eating disorders. Currently, research studies are accruing information about sex differences as well as differences across ethnic and racial populations for those with eating disorders.[7-9] Let us hope that fewer and fewer clinicians have to face the deaths of their patients by standing by the now well-established ethical norm that decisionally capacitated adults have the moral and legal right to have their decisions honored, even if they are honored unto death.

We certainly hope you enjoy this issue and are challenged by the many complex topics raised. Take care and stay healthy and safe.

Sincerely,

Evan

Evan G. DeRenzo, PhD
Editor-in-Chief
Journal of Hospital Ethics
John J. Lynch, MD Center for Ethics
MedStar Health, Washington, DC

REFERENCES

1. Van Eeden AE, Koeken Dv, Hoek HW. Incidence, prevalence and mortality of anorexia nervosa and bulimia nervosa. *Curr Opin Psychiatry* 2021, 34:515-524)

2. Mathis KJ, Costa CB, Xandre P. Treating individuals with eating disorders: Part 1. *J Psychosoc Nurs Ment Health Serv.* 2020 Mar 1;58(3):7-13.

3. Mitchell JE, Peterson CB. Anorexia Nervosa. *N Engl J Med.* 2020. April 2; 382:1343-1351.

4. Accurso EC, Mu KJ, Landsverk J, Guydish J. Adaptation to family-based treatment for Medicaid – insured youth with anorexia nervosa in publicly-funded settings: Protocol for a mixed methods implementation scale-out pilot study. *J Eat Disord.* 2021 Aug 13;9 (1):99.

5. Haynos AF, Wang SB, LeMay-Russell S, Lavender JM, Pearson CM, Mathis KJ, Peterson CB, Crow SJ. An empiricall taxonomy of reward response patterns in a transdiagnostic eating disorder sample. *Science Direct: Eating Behaviors.* 2021. Aug. 42:101531.

6. Costa CB, Xandre PE, Mathis KJ. Treating individuals with eating disorders: Part 2. *J Psychosoc Nurs Ment Health Serv.* 2020. Apr 1:58(4):9-15.

7. Bell BM, Spruijt-Metz D, Naya CH, Lane CJ, Wen CKF, Davis JN, Weigensberg MJ. The mediating role of emotional eating in the relationship between perceived stress and dietary intake quality in Hispanic/ Latino adolescents. *Science Direct: Eating Behaviors* 2021. Aug; 42:101537.

8. Marquez FD, Risica PM, Mathis KJ, Sullivan A, Gobin AP, Tyrka AR. Do measures of healthy eating differ in survivors of early adversity? *Science Direct: Appetite.* 2021; July 1;162:105180.

9. Timko CA, DeFillipp L, Dakanalis A. Sex diffeences in adolescent anorexia and Bulimia Nervosa: Beyond the signs and symptoms. *Curr Psychiatry Rep.* 2020. Jan. 12;21(1):1

FEATURES

Operationalizing Scarce Resource Allocation: A Lived Experience

Lindsay Semler, DNP, RN, CCRN, HEC-C, NPD-BC, WTA-C

Abstract

This article describes the implementation of scarce resource allocation at the largest health system in Oklahoma. Although our state did not declare crisis standards of care, we felt it prudent, as a trial, to completely operationalize the scarce resource allocation process. This allowed our executive, clinical, and ethical leaders to address gaps, barriers, and challenges associated with scarce resource allocation, and develop a robust process that is ready for implementation should the need arise. This article reviews Scarce Resource Allocation Team (SRAT) selection and training, organizational support for the SRATs, challenges and solutions to the scarce resource allocation framework, data and documentation recommendations, collaboration with state and regional hospitals as well as the state government, and addressing moral distress in clinicians. With COVID-19 ongoing for the foreseeable future, as well as the threat of future pandemics, I will argue that it is the ethical responsibility of healthcare organizations and nursing leaders to have an allocation process in place.

Introduction

As the COVID-19 pandemic continues around the United States (US) and the globe, and nursing shortages increase, scarce resource allocation remains a relevant topic. Numerous states across the US have published their scarce resource allocation protocols that contain varying elements of ethical frameworks, health equity, and identity-blind allocation of resources.[1-4] These frameworks use a systems approach to address shortages of space, stuff, and staff, and to prioritize patients with a good chance of survival who will not exhaust extensive resources.[5]

While these state-specific frameworks demonstrate incredible thought and insight, less has been written on the nuances of how an organization would operationalize and implement these frameworks. How are data pulled from the electronic medical record (EMR) in a meaningful and efficient way? How are Scarce Resource Allocation Teams (SRATs) trained? How are ethical principles such as justice and nonmaleficence balanced with clinical utility and the use of validated tools? This article shares one organization's own experience in operationalizing a triage framework, and provides guidance for other institutions as they work through implementing or planning for triage frameworks in their own region.

Many crisis standards of care guidelines use a version of the White/Hopkins model.[6] This model uses the Sequential Organ Failure Assessment (SOFA) Score, as well as short-term indicators of mortality, to assign priority scores to patients who require a scarce resource. The White/Hopkins model also suggests the use of a Scarce Resource Allocation Team (SRAT) to triage patients based on their priority score, and thus relieve bedside clinicians from the burden of scarce resource allocation. As the pandemic has progressed and new evidence has emerged, the framework has undergone modifications to better address social inequities and promote justice across all populations. The development of an ethical framework is complicated by the lack of a universal, objective, reliable, and valid scoring system that accurately predicts mortality for all disease states. Many states have adopted the use of the SOFA score as a predictor of short-term mortality in the absence of a more robust tool. The National Academy of Medicine, along with other thought leaders, recommend a principle-based approach with the use of a clinical expert.[7] Other modifications such as using the Area Deprivation Index (ADI),[8] consideration of essential worker status, and life-years have emerged as further attempts to uphold the principle of justice.[6, 9]

There is a dearth of information regarding the operational nuances and challenges of implementing scarce resource allocation strategies. Our organization started a scarce resource allocation protocol on the week of 12/28/20 in two COVID intensive care units (ICUs) (around 28 patients per day total) to pilot the allocation framework and the SRAT functioning. Since then, our team has gained valuable insight and has developed recommendations for other organizations to adopt and implement our scarce resource allocation framework.

Scarce Resource Allocation Team (SRAT): Selection and Training

SRAT Member Characteristics and Selection

White and Lo[6] provide recommendations on the characteristics and responsibilities of the team members involved in allocating scarce resources, which our team used to develop our SRAT. These team members include a Triage Officer, a Nursing representative, and an Ethics Committee representative. Each member has his or her own responsibilities in implementing the triage framework, and may vary between organizations depending on team members' comfort and abilities **(Figure 1)**:

Figure 1: Scarce Resource Allocation Team Members and Responsibilities

Triage Officer:

- Is not involved with the patient's care
- The patients' treating physician should not make triage decisions in order to enhance objectivity, avoid conflicts of commitments, and minimize moral distress
- Assess all patients for clinical condition, relevant co-morbidities, and framework exceptions
- Collaborates with bedside physicians
- Makes decisions in collaboration with the rest of the SRA team according to the allocation framework in order to benefit the greatest number of patients
- Informs the patient's attending about the triage decision, then collaborates with the attending to determine the best approach to inform the individual and family

Nursing Representative:

- Abstracts data from EMR
- Content expert for critical care patients
- Makes decisions in collaboration with the rest of the SRA team according to the allocation framework in order to benefit the greatest number of patients

Ethics Committee Representative:

- Oversees the triage process
- Content expert on the triage framework
- Serves as the ethical voice of questioning during resource allocation
- Help lead and guide the team through the allocation process, and collaborates with the rest of the SRA team to allocate resources and benefit the greatest number of patients
- Communicates with Incident Command and leadership as needed

All members are responsible for ensuring documentation of SRA patients, scores, brief description of discussion, and decisions made.

The National Academy of Medicine has recommended that a critical care consultant, Chief Medical Officer (CMO), or on-call expert be available for allocation decisions.[7] The Triage Officer in this model would represent that critical care expert, with the addition of a nurse and an ethics consultant to ensure ethical allocation decision-making processes, as well as adding an essential interdisciplinary element. **In addition to listing their responsibilities, below are some of the characteristics sought in individuals assigned to these roles:**

Triage Officer: The Triage Officer should be a physician with established expertise in the management of critically ill patients, outstanding leadership ability, and effective communication and conflict resolution skills. During a high-stress, high-urgency, and emotionally charged situation, bedside clinicians may respond more favorably to a highly-regarded expert than otherwise. Potential Triage Officers should also consider their level of comfort in making rapid, high-stakes assessments and decisions.

Nurse: The nurse should have significant critical care experience, and able to quickly and efficiently navigate the electronic medical record (EMR) to retrieve data.

Ethics Committee Representative: The Ethics Committee member should be one with a basic level of familiarity navigating the EMR, proficiency in computer usage for documentation, the training to calculate SOFA and priority scores, and comfort with applying ethical principles to clinical practice.

SRAT members should be free from clinical responsibilities while on-call for SRAT.

Training

In order to prepare SRAT members for their roles, a multi-step process was implemented. First, an online training module that reviewed ethical principles and the impact of implicit bias on healthcare decision-making was developed and assigned to SRAT members. SRAT members also received the allocation framework document to review. After they completed the online module, SRAT members attended live one-hour training sessions that reviewed the allocation framework and real-life application of the framework to current COVID ICU patients, as well as SRAT members' respective roles and responsibilities.

Organizational Support

Given the difficult decisions SRAT members could face, executive leadership ensured the availability of organizational resources, such as peer counseling or an Employee Assistance Program (EAP) to provide psychological support to SRAT members and other clinicians affected by allocation decisions. Our organization has a Behavioral Health support team who would be available for individual or group debriefing, if needed.

In cases of resource withdrawal that result in patient decline or death, the level of moral distress can be expected to increase for all parties involved, due to the morally complex nature of triaging life-saving medical treatment.[10] Should a critical resource need to be withdrawn from a patient, a point person should be identified to:

Ensure a chaplain, social work, or case management referral is entered for the family (ideally before the resource is withdrawn, in order to be present for the communication of the allocation decision and support the family and caregivers throughout the process).

Refer all members involved in the case to an Employee Assistance Program or similar, and hold a critical incident debriefing within one week of the withdrawal for all involved clinicians, SRAT members, legal counsel, and executive leadership.

Allocation Framework

SOFA Scoring: Utility and Challenges

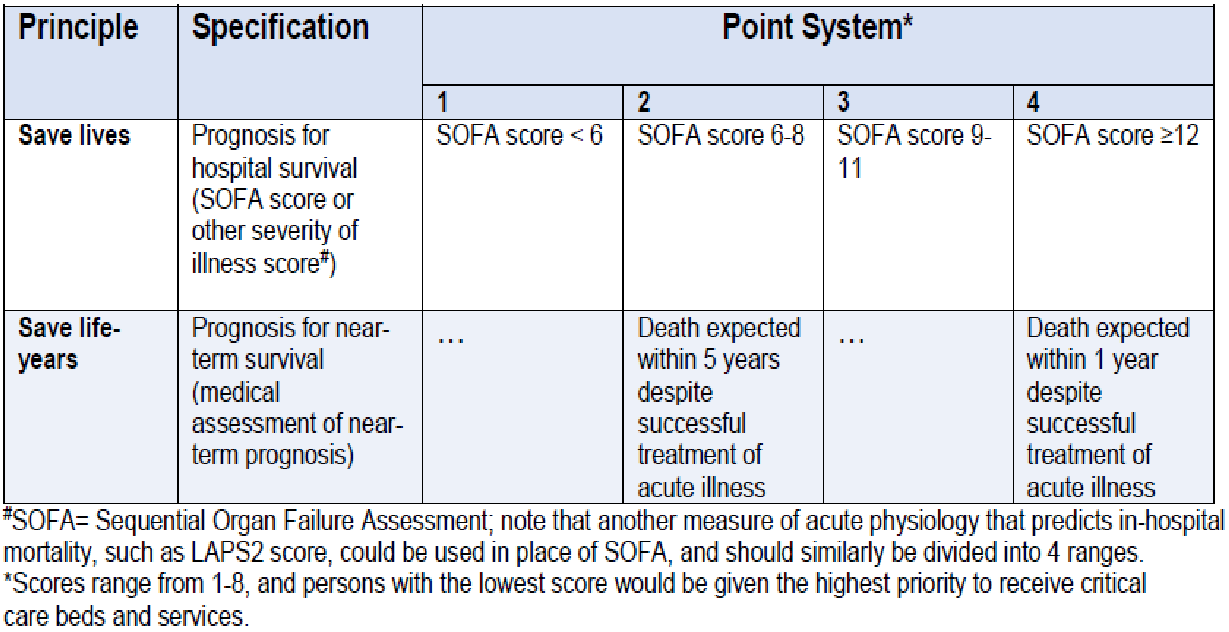
Our framework sought to reflect the highest level of clinical relevance and utility, as well as ethical principles such as beneficence, nonmaleficence, and justice. The White/Hopkins model **(Figure 2 on page 67)** has been adopted across the country. Along with many other states, Oklahoma adopted a version of the framework to allocate resources.

The SOFA score was originally validated for use in sepsis, and has not performed well in predicting outcomes for patients in respiratory failure.[11] The National Academies of Medicine also discourages basing allocation decisions on a single score such as SOFA.[12] However, despite its limited predicative ability, it does offer a reasonable measure of anticipatable organ failure for any patient experiencing an acute illness. The SOFA score can also be tracked over time, giving one indication of a patient's illness trajectory. In this way, the SOFA score can help to inform, but not unduly influence, decision-making. Along with many states, Oklahoma included the SOFA score as one measure of short-term mortality.

The original White/Hopkins model included comorbidities that impact long-term survival, which has been challenged and subsequently removed by our institution. Our organization initially used the updated White and Lo model that included a) SOFA score (1-4 points) and b) "death expected within 1 year from end-stage condition" (4 points). However, our initial review of patients in the COVID ICUs resulted in nearly all patients being categorized as high-priority, and between 0-1 patients per day in the intermediate priority category.

Figure 2: **Original White/Hopkins Model**

Used with permission from Dr. Douglas White. White, D.B. and Lo, B. (2020). A framework for rationing ventilators and critical care beds during the COVID-19 pandemic. Journal of the American Medical Association. Published online March 27th, 2020.



Principle	**Specification**	**Point System***			
		1	**2**	**3**	**4**
Save lives	Prognosis for hospital survival (SOFA score or other severity of illness score[#])	SOFA score < 6	SOFA score 6-8	SOFA score 9-11	SOFA score ≥12
Save life-years	Prognosis for near-term survival (medical assessment of near-term prognosis)	…	Death expected within 5 years despite successful treatment of acute illness	…	Death expected within 1 year despite successful treatment of acute illness

[#]SOFA= Sequential Organ Failure Assessment; note that another measure of acute physiology that predicts in-hospital mortality, such as LAPS2 score, could be used in place of SOFA, and should similarly be divided into 4 ranges.
*Scores range from 1-8, and persons with the lowest score would be given the highest priority to receive critical care beds and services.

Furthermore, our Triage Officers and clinicians remarked that priority scores did not seem to accurately reflect the true clinical condition of the patient, as the SOFA score was the single contributor to the priority score in all patients who did not have a co-morbidity that limited life expectancy to <1 year. The clinical and ethics experts at our organization agreed with national recommendations to not base allocation decisions on predictors of long-term mortality, but it was clear that an adjustment needed to be made in order to maximize the clinical utility of the framework. Therefore, we elected to replace the two-point score of "death expected within 5 years" **(as shown in Figure 2)** with co-morbidities that evidence has shown to impact the severity of illness and/or survival to discharge for a patient's principle diagnosis **(Figure 3 on page 68)**. This change resulted in a significant redistribution of priority scores and aligned much more closely with the patients' illness trajectory as described by the bedside clinicians.

It must be noted that the final priority score is one contributing factor in the decision-making process for resource allocation and is not the only basis for allocation. In circumstances that a scarce resource would need to be reallocated, the Triage Officer would review the priority scores of all the patients using or requiring the scarce resource, and then bring that information into a conversation with the bedside clinician(s). The bedside clinician and the Triage Officer would collaborate in evaluating the patients least likely to survive based on objective measures of short-term mortality combined with expert clinical judgment. This model allows for not only the highest degree of justice by using quantitative, objective data to evaluate all patients in the same fashion, but also utilizes a utility and justice-based system that recognizes and accounts for the value of expert clinician judgment.

SOFA Score Alterations

A barrier in utilizing SOFA for triage is that due to its limited parameters, the original scoring system cannot be applied to all patients. In order for a triage system to be fair to all individuals, the system must apply to all patients, regardless of diagnosis, who require or are using a scarce resource. How are patients who are on extracorporeal membrane oxygenation (ECMO) scored, or patients on one of the vasopressors not noted in the SOFA score such as core such as vasopressin or phenylephrine? (**Figure 4 on page 70** shows the adapted SOFA score used by our institution.)

Patients on veno-venous (VV) ECMO generally receive a score of 4 on the SOFA score, as calculated by the P/F ratio (the arterial pO2 divided by the FiO2). Since these patients receive oxygenation from both a ventilator and the ECMO circuit, each of which may be delivering different FiO2, it was decided to use the higher FiO2 to calculate the P/F ratio. For example, a patient on 100% via the ECMO circuit and 40% on the ventilator would have the 100% FiO2 used to calculate the P/F ratio. In this way, it was easier to more accurately capture the respiratory status of the patient, especially during ECMO weaning trials when the lungs may be showing improvement.

Figure 3: Adapted Allocation Model

Triage Framework to Promote Population Health Outcomes and Justice

Adapted with permission from Dr. Douglas White; White, D., and Lo, B. (2020). Mitigating Inequities and Saving Lives with ICU Triage during the COVID-19 Pandemic. American Journal of Respiratory and Critical Care Medicine, 203(3).

Principle	Criterion	Point System*			
		+1	**+2**	**+3**	**+4**
PROMOTE POPULATION HEALTH OUTCOMNES	Prognosis for hospital survival (assessed using a validated severity of illness score)	**Quartile 1** lowest risk of death (i.e., risk of death <25%) SOFA <6 PELOD 2 <12	**Quartile 2** (i.e., risk of death 25-49%) SOFA 6-9 PELOD 2 12-13	**Quartile 3** (i.e., risk of death 50%-75%) SOFA 10-12 PELOD 2 14-16	**Quartile 4-** highest risk of death (i.e., risk of death >75%) SOFA >12 PELOD 2 ≥17
	Presence of end stage medical condition (medical assessment of near-term prognosis)	…	**Co-morbidities that evidence shows impact survival to discharge*****	…	**Death expected within 1 year from end stage Condition**
	After clinical priority points are calculated, two or more patients may have the same priority score. ***Best clinical judgment (discussion between Triage Officer and bedside clinician) will then be applied in order to maximize equity and clinical outcomes using best available evidence and expert opinion****. Should the patients remain in a comparable clinical state/ prognosis and similar priority scores, the following tiebreakers may be applied.*				
PROMOTE JUSTICE/EQUITY: POTENTIAL BREAKERS	Correction for structural inequities using Area Deprivation Index (ADI)	**Tiebreaker:** priority is given to the patient with an ADI of 8,9, or 10 (on 1-10 scale)			
	Priority to essential workers	**Tiebreaker**: a worker essential to the pandemic response in a high-risk occupation			
	Priority to those who've had the least chance to live through life's stages	**Tiebreaker:** In the event that two patients have identical Triage Priority Scores, give priority to the patient who has had the least opportunity to experience life's stages. However, an age difference of ≥10 years must be present between two patients in order for this tiebreaker to take effect.			
	Equal chances	**Second tiebreaker:** In the event that two patients have identical Triage Priority Scores and no other tiebreaker can be applied, use random selection to determine who receives the resource.			

Patients on veno-arterial (VA) ECMO received scoring consistent with respiratory status as described above, and received 4 points on the SOFA score for cardiovascular. Likewise, any patient with temporary mechanical circulatory support, such as an intra-aortic balloon pump (IABP) or temporary ventricular assist device (VAD), received 4 points in the cardiovascular section. However, it is important to note that patients with a durable VAD would not receive the 4 points in the cardiovascular section simply for having a durable VAD, as the SOFA score should reflect acute processes. However, a patient with a VAD (and therefore pre-existing heart failure, however well managed), may receive the additional 2 points in the priority score if heart failure is a co-morbidity that increases severity of illness or survival to discharge for the patient's primary diagnosis. Patients with end-stage renal disease (ESRD) on hemodialysis or peritoneal dialysis will generally receive 4 points on the SOFA score, but not the additional 2 points for that co-morbidity to avoid placing the patient in double jeopardy. The addition of the norepinephrine equivalents of phenylephrine and vasopressin allowed us to capture patients who were on those medications.[12] Patients on more than one vasopressor received 4 points.

Other alterations to the SOFA score were related to lab values. The Modified Sequential Organ Failure Assessment (MSOFA) tool is validated for triage, but neglects important body systems often measured in critical care such as coagulation for the sake of rapidity of evaluation. However, our clinician leaders were unable to correlate MSOFA scores with appropriate 0-4 scores on the White/Hopkins model due to variations in predictive mortality. Therefore, the SOFA and MSOFA were combined **(Figure 4 on page 70)**. For example, patients with no PaO2 would alternatively be scored using the S/F ratio (O2 saturation as measured by pulse oximetry divided by the FiO2). Any category that cannot be scored; for example, no platelet or creatinine value drawn that day, would yield a score of zero in that category.

The Glasgow Coma Scale (GCS) also presented implementation challenges. The GCS pulled from the EMR often reflects the score of the patient while intubated, sedated, paralyzed, or all three. Because of the artificial and medically induced lower GCS score, our team agreed with Grissom et al.[13] that the last known score before intubation should be used. This can be difficult to discover if the patient was intubated in the field. Additionally, patients who had a normal GCS on admission but had since developed COVID-induced encephalopathy or anoxic brain injury, but remain sedated, are the most challenging to assess. In these instances, the Triage Officer reviewed the intensivists' and neurologists' notes and electroencephalograph (EEG) results, and would potentially speak to the bedside clinicians, to attempt to determine an appropriate GCS score. Our team also felt that a chronic neurological process that affects a GCS score (e.g. dementia causing disorientation, or a non-verbal patient) should not be reflected in a patient's SOFA score, which is intended to reflect acute deficits. Unless there is evidence of an acute neurological process **(reflected in Figure 4)**, the patient would receive a score of 15.

Priority Scoring and Tiebreaking

After the SOFA score was calculated, patients were assigned a priority score based on the framework outlined in **Figure 3**. If resources needed to be withdrawn, and two or more patients had identical priority scores, the tiebreakers listed in Figure 3 would be applied. The tiebreakers served to promote justice by prioritizing those patients with less favorable area deprivation index scores, essential workers, and those who have had the least chance to live through life's stages.[6,8,9]

Data and Documentation

Manually obtaining data from the EMR such as lab values and vital signs each day and, for each patient can be incredibly time-consuming, so our team found that developing a report to automatically retrieve many data elements could significantly reduce time burden. Our informatics team was able to build a report that captured all SOFA score elements, as well as code status, palliative care consult status, days on ventilator, presence of advanced therapy (ECMO, CRRT, VAD), ICU length of stay, and patient's address (for ADI calculation). The data were pulled by the report and then exported to an electronic spreadsheet. One spreadsheet was created with each tab representing a different day in order to track and "re-assess" patients. One limitation to our report was that instead of pulling the "worst" data point in the past 24 hours (as the SOFA score recommends), we were only able to receive the last data point when the report was run. However, our ethics committee felt that as long as patients were measured the same way, that this deviation was acceptable.

Collaboration With State and Regional Hospitals

During times of crisis, organizations who may be normally in competition often work together to care for the people of their region. Our organization used the state's Hospital Association to create a working group of clinical and ethics experts from a majority of the state's institutions to discuss allocation frameworks. This group was able to reach general consensus and align institutional frameworks to ensure consistency in triage methods across the state. Another group of organizational leaders collaborated to ensure that crisis care "triggers" were defined similarly across the state.

Figure 4: **Adapted SOFA Scoring Guidelines** (Next page)

SOFA Score	0	1	2	3	4
Respiration					
PaO2: FiO2	>400	301-400	201-300	101-200	≤100
SpO2: FiO2	>400	≤400	≤315	≤235	≤150 or on ECMO
Coagulation					
Platelets (x10^3/mm^3)	>150	101-150	51-100	21-50	≤20
Liver Bilirubin (mg/dL)	<1.2 No jaundice	1.2-1.9	2.0-5.9	6.0-11.9 Presence of jaundice	>12.0
Cardiovascular	No hypotension (MAP ≥70)	MAP <70 mmHg	Dopamine ≤5.0 mcg/kg/min Any dose dobutamine Any dose milrinone	(Doses in mcg/kg/min) Dopamine >5.0 or Epinephrine ≤0.1 or Norepinephrine ≤0.1 or phenylephrine ≤1 or vasopressin ≤0.04 units/min	(Doses in mcg/kg/min) Dopamine >15.0 or Epinephrine >0.1 or Norepinephrine >0.1 or phenylephrine >1 or vasopressin >0.04 units/min or on temporary mechanical support (IABP, Impella®, VA ECMO) or on >1 vasopressor
Neuro					
GCS (With guidance for scoring acute neurological processes when patient is intubated/ non-verbal)	15	13-14 Metabolic encephalopathy (hindrance but fairly easily recoverable)	10-12 Minor neurological event/ deficit	6-9 Major neurological deficit/ CVA	3-5 Non-medication induced coma
Renal					
Creatinine (mg/dL)	<1.2	1.2-1.9	2.0-3.4	3.5-4.9	>5.0
Urine output (last 24 hours)				<500 mLs	<200 mLs

Moral Distress and Caring for the Clinician

Organizational leadership should recognize the impact of the pandemic and the impact that allocation decisions would have on bedside clinicians. Moral distress, first defined as "knowing the right thing to do, but being unable to do it"[14] tends to occur more frequently during crises and pandemics.[10] Leaders throughout an organization should take steps to address moral distress, caregiver fatigue, burnout, post-traumatic stress disorder (PTSD), and develop programs to enhance resilience. Institutions have available to them numerous resources from national organizations such as the National Academy of Medicine, Sigma, and the American Association of Critical Care Nurses, to assist them in developing resiliency and peer support programs and addressing moral distress.[15-18] Our institution created optional webinars devoted to "Ethics in Pandemic" and the problem of implicit bias that were available to every caregiver, along with education and other resources for moral distress, which were posted on nursing and physician associated webpages. The author also held sessions on moral distress for nurse leaders to assist them in supporting their staff, and moral distress rounds were conducted on various units throughout the health system.

Future Opportunities and Discussion

While our described approach is a beginning, more research is needed in the operationalization of triage processes during a pandemic. Important next steps include the creation of a triage tool that can be used instead of SOFA, or the validation of an altered SOFA score.

During a time of uncertainty, changing policies, and the constant influx of new literature and best practices, the ability of senior hospital leadership and scarce resource allocation teams to functionally implement crisis standards of care is of utmost priority. Any allocation framework should be frequently re-evaluated and updated according to the best available evidence. Between the time of this article's submission and publication, there will have undoubtably been numerous changes to our organization's framework and thus approach to scarce resource allocation. What should not change, however, is a devotion to maintaining the highest levels of integrity and ethical clinical practice.

AUTHOR

Lindsay Semler, DNP, RN, CCRN, HEC-C, NPD-BC, WTA-C is Systems Manager of Clinical Ethics at INTEGRIS Health. Dr. Semler graduated with her Doctor of Nursing Practice from Johns Hopkins School of Nursing with a focus on moral distress in critical care nurses. She continues to work at Johns Hopkins as adjunct faculty. Dr. Semler is board certified in Critical Care, Healthcare Ethics Consultation, Nursing Professional Development, and as a Wound Treatment Associate. She also attained a certificate from GeorgetownX in Bioethics, and a certificate from the University of Washington's Advanced Training for Healthcare Ethics program.

REFERENCES

1. Interim Pennsylvania Crisis Standards of Care for Pandemic Guidelines. March 22, 2020. Accessed February 22, 2022. https://int.nyt.com/data/documenthelper/6850-pennsylvania-triage-guidelines/02cb4c58460e57ea9f05/optimized/full.pdf#page=1

2. Daugherty -Biddison L, Gwon H, Regenberg A, Schoch-Spana M., Toner E. Maryland Framework for the Allocation of Scarce Life-sustaining Medical Resources in a Catastrophic Public Health Emergency. August 24, 2017. Accessed February 22, 2022. http://bioethicstoday.org/wp-content/uploads/2020/03/Daugherty-Maryland-framework-PH-emergency-2017.pdf

3. State of Indiana. 2020 Crisis Standards on Patient Care Guidance: Triage and Ventilator Allocation Guidelines. April 3, 2020. Downloaded December 8, 2020. Indiana-Vent-Allocation-FINAL-04.03.2020.pdf (hallrender.com)

4. Manchanda ECC, Sanky C, Appel JM. Crisis standards of care in the USA: A systematic review and implications for equity amidst COVID-19. *Journal of Racial and Ethnic Health Disparities.* 2020. Published online.

5. Society of Critical Care Medicine (SCCM). Disaster triage and allocation of scarce resources. 2013. Accessed December 1, 2020. https://covid19.sccm.org/Presentations/Disaster-Triage-Allocation-Scarce-Resources/story_html5.html?lms=1

6. White DB, Lo B. A framework for rationing ventilators and critical care beds during the COVID-19 pandemic. *JAMA.* 2020;323(18):1773-1774. doi:10.1001/jama.2020.5046

7. National Academy of Medicine. Crisis standards of care: Quick guide for emergency planners. December 2020. Accessed January 4, 2020. https://nam.edu/wp-content/uploads/2020/12/csc-planner-guide_updated.pdf

8. Singh GK. (2003). Area deprivation and widening inequalities in US mortality, 1969-1998. *American Journal of Public Health*. 2003;93(7): 1137-1143.

9. White DB, Lo b. Mitigating inequities and saving lives with ICU triage during the COVID-19 pandemic. American *Journal of Respiratory and Critical Care Medicine*. 2021;203(3):287-295.

10. Canadian Medical Association. COVID-19 and Moral Distress. Accessed August 8, 2021. https://www.cma.ca/sites/default/files/pdf/Moral-Distress-E.pdf

11. Lambden S, Laterre PF, Levy MM, Francois B. The SOFA score—development, utility and challenges of accurate assessment in clinical trials. *Critical Care*, 2019;23(374). doi: https://doi.org/10.1186/s13054-019-2663-7. https://ccforum.biomedcentral.com/articles/10.1186/s13054-019-2663-7

12. National Academy of Medicine. Crisis Standards of Care, COVID-19 Issue Summary. 2020. Accessed January 2020. https://nam.edu/wp-content/uploads/2020/12/csc-issue-summary_updated.pdf

13. Grissom CK, Browm,SM, Kuttler KG, Boltax, JP, Jones J, Jephson AR, Orme JF. A modified sequential organ failure assessment (MSOFA) score for critical care triage. *Disaster Medicine and Public Health Preparedness*; 2010;4(4). doi:10.1001/dmp.2010.40.

14. Jameton, A. (1984). *Nursing Practice: The Ethical Issues.* Englewood Cliffs, NJ: Prentice-Hall; 1984:6

15. National Academy of Medicine. Action collaborative on clinician well-being and resilience. 2021. Accessed November 26, 2021. https://nam.edu/initiatives/clinician-resilience-and-well-being/

16. American Association of Critical Care Nurses. Well-being in uncertain times. 2021. Accessed November 26, 2021. https://www.aacn.org/clinical-resources/well-being

17. American Association of Critical Care Nurses. Resources for moral distress. Accessed November 26, 2021. https://www.aacn.org/clinical-resources/moral-distress

18. Sigma. Find your forward: Resources for advocacy and strength. Accessed November 26, 2021. https://nursingcentered.sigmanursing.org/find-your-forward

To Feed or Not to Feed: The Effect of Anorexia Nervosa on Autonomous Decision Making

Eli Weber, PhD, MA, HEC-C and Jo Everett, MD

Abstract

Anorexia Nervosa is one of the most lethal psychiatric conditions. Weight restoration and psychological treatment are complementary and crucial for treating patients with this condition. However, many patients with anorexia nervosa decline to sufficiently increase their oral intake, even when they are seeking treatment for their condition. The treatment team is thereby left with two undesirable treatment pathways—either accept the patient's decision despite concerns that their choice is unduly influenced by their underlying psychiatric disorder, and therefore not an autonomous choice, or override the patient's choice, because it is not autonomous, and compel artificial nutrition. We discuss the clinical and ethical challenges that arise when attempting to treat this difficult patient population, and offer a solution to this ethical dilemma that allows us to respect patient autonomy without undermining the patient's recovery potential.

Introduction

Anorexia nervosa is a potentially life-threatening mental illness which revolves around restriction of energy intake resulting in significantly low body weight. One of the key components of anorexia nervosa is the intense fear of gaining weight or becoming fat as well as a disturbance in the way in which one's body shape is experienced.[1] According to the National Institute of Mental Health, the lifetime prevalence of anorexia nervosa in adults is 0.6%.[2] The disorder often begins in adolescence or young adulthood, and approximately one third of cases follow a chronic course.[3] Around 10-20% of patients die from complications of anorexia nervosa.[4] One of the most challenging aspects in treating patients with anorexia nervosa is their reluctance to seek or accept treatment. Due to the serious medical issues that can arise due to self-starvation, these patients frequently present in the primary care setting and emergency departments with previously unrecognized eating disorders. Patients struggling with anorexia nervosa may go to great lengths to avoid clinical diagnosis of their underweight status, for instance layering clothing to give the appearance of being heavier, drinking excessive amounts of water prior to being weighed, and even taping weights to themselves.[3] Medical complications are common, especially in severe cases of anorexia nervosa, and can affect every organ system.

Treatment for anorexia nervosa typically focuses on weight restoration in order to avoid many of the potentially lethal medical complications of starvation. As discussed earlier, patients struggling with anorexia nervosa can be resistant to treatment. Hospitalization may be voluntary or involuntary. Involuntary hospitalization is often used when the treatment team feels the patient is a danger to themselves due to the medical severity of illness. An involuntary hospital admission does not require compulsory treatment, such as forced feeding by nasogastric tube. Patients who are severely underweight, less than 75% of expected body weight, often require inpatient or partial hospitalization care for refeeding. Care must be taken to avoid refeeding syndrome, a complication which can result in heart failure, delirium, and even death.[1,2,4]

The Effects of Anorexia on Decision-Making Capabilities

In order to appreciate how anorexia can affect one's decision-making capabilities, and why this gives rise to an ethical dilemma in the treatment of this disorder, we should first say a bit more about decision-making capacity in general. Capacity to make one's own medical decisions requires that at least four criteria are satisfied.[5] First, the patient must be capable of expressing a choice. This is a relatively straightforward criterion that many otherwise impaired patients can satisfy. Next, the patient must understand the medical facts that are relevant to the decision at hand. For example, if the decision concerns a procedure, the patient should have a basic understanding of what the procedure involves, what part of the body will be affected, what problem the procedure is correcting or addressing, etc. Third, the patient must demonstrate that they appreciate the consequences or implications of their choice. A patient who decides to undergo a procedure that requires general anesthesia, for instance, should be able to appreciate that agreeing to the procedure implies agreeing to general anesthesia as well. Finally, decision-making capacity requires that the patient can provide a coherent rationale for their decision, i.e., give reasons for why they are making a particular choice.

The ethical significance of decision-making capacity cannot be overstated. Western approaches to medical ethics emphasize the importance of patient autonomy to a significant degree, and decision-making capacity is a prerequisite for making autonomous choices. When patients with decision-making capacity make autonomous choices, the medical team has an ethical duty to honor and respect these choices.[6]

Patients with anorexia nervosa threaten to confound this traditional understanding of decision-making capacity as a prerequisite for autonomous choice, as anorexia nervosa directly influences how patients formulate their core values. For example, in a study by Tan et al.,[7] patients with anorexia attached negative value to "fatness," which they perceived as highly undesirable and associated with being lazy and lacking self-control, but also more extreme negative associations like being a failure or being unlovable. Patients in this study also placed thinness at the top of their value hierarchy, such that their drive for thinness took precedence over all other parts of their lives. In many cases physical illness associated with extreme weight loss was viewed as a sign of success, rather than an indicator of serious dysfunction.

Anorexia nervosa also affects the patient's conception of their own personal identity.[8] Patients with anorexia nervosa often identify their disorder as a significant component of their sense of self, of who they are and their place in the world. They tend to view their personal narrative, and their own sense of self-worth through the lens of anorexia nervosa, and regard themselves as a success or failure, in general, relative to their extreme weight loss. Patients with anorexia nervosa have a sense that their personality might change completely if they were to receive treatment, that they would somehow be a different person altogether if they did not have this condition. Treatment, on this view, is a threat to one's core values and one's sense of self. It is no surprise that many patients with anorexia nervosa opt to not pursue artificial nutrition as a component of their treatment.

These features of anorexia nervosa are what confound our traditional conceptions of patient autonomy and decision-making capacity. Despite their severe psychological impairments, patients with anorexia nervosa are often able to satisfy standard criteria for decision-making capacity, even when the decisions being made pertain to the treatment of anorexia. Many patients with anorexia nervosa are well informed about their condition and its associated risks, and they can reason from their values to their choices in perfectly coherent ways. Patients with anorexia nervosa value thinness above all else, so when they refuse treatment for their condition, they are making a decision that is consistent with their core values and reflective of their own identity. They can reason from the value they place on thinness to a decision not to eat, and they appreciate, and sometimes hope for the harmful effects of this choice, since this is an indicator that they are succeeding in the pursuit of their deeply valued goals. If not for the dysfunctional nature of their choices, the anorexic patient's decision-making process is often not merely sufficient for decision-making capacity, but paradigmatic of the ideal.

One important caveat should be noted. In some cases, patients with severe anorexia nervosa suffer from metabolic encephalopathy due to malnutrition. These patients are an exception to the above analysis, as they clearly and straightforwardly lack the capacity to make their own medical decisions. However, these patients are essentially the exception which proves the rule—setting aside cases where capacity is clearly lacking for medical reasons, many patients with anorexia nervosa can satisfy standard criteria for autonomous decision making despite their disorder.

The Ethical Dilemma of Forced Feeding for Patients With Anorexia

It is difficult to determine whether anorexic patients are capable of autonomous choice about treatment for their disorder. Outside of patients who are obviously incapacitated, many anorexic patients exhibit the kind of values-based reasoning which is characteristic of autonomous choice, yet their choices themselves are deeply dysfunctional. This difficulty, in turn, gives rise to an ethical dilemma in the clinical setting. Many patients with anorexia nervosa fail to meet their nutritional needs via oral intake, even when under direct medical supervision. When patients with anorexia nervosa cannot meet their nutritional needs despite various non-invasive and therapeutic interventions, the next step is often to consider artificial nutrition, especially for patients who are demonstrating serious or life-threatening complications of prolonged malnutrition. However, informed consent is usually required for artificial nutrition. Many patients with anorexia nervosa, unsurprisingly, decline artificial nutrition as a treatment option, in which case the medical team has the option to regard this an autonomous choice, respect the patient's right to make it, and allow the patient to undergo the harms associated with severe malnutrition, even to the point of the patient's own death. This is a difficult outcome for many providers to accept, as it amounts to allowing the patient's illness to influence their choices in ways that lead to their own demise. Respecting a patient's autonomous choice to die of anorexia nervosa is at best a difficult outcome to accept; at worst, it is an unethical approach to patient care.

The alternative course of action hardly fares better for either patient or provider. When the anorexic patient chooses to forego artificial nutrition, the medical team may regard this decision as not an autonomous choice, for reasons we have already identified, and therefore not a decision that demands respect. In such cases, the medical team may seek informed consent from an appropriate surrogate, and compel artificial nutrition against the patient's expressed refusal. The ethical justification in such cases is that the benefits of artificial nutrition outweigh the harms of compelling it, and informed consent is obtained from an appropriate surrogate since the patient lacks capacity to make an informed choice. On this account, the lack of autonomous choice plus the benefits of artificial nutrition are thought to justify this otherwise highly invasive treatment strategy.

One might look to legal standards to resolve this dilemma.[9] However, from a legal perspective there is nothing special or unique about this patient population or their clinical circumstances. Patients with anorexia nervosa are like any other adult patient—whether the medical team is obligated to respect their choices depends on whether those choices are autonomous, which turns crucially on whether these patients have the capacity to make their own medical decisions. A review of the existing case literature[10-11] reveals myriad examples of both approaches to treatment. Some patients with anorexia are compelled to receive artificial nutrition, while others refuse, and this choice is respected even to the point of their own death. Thiel and Paul report a case where a patient receiving compulsory treatment was repeatedly isolated and physically restrained for feeding, but gained only 1.11 kg in 178 days.[12] On the opposite extreme, Jackson reports on a case in which a woman with anorexia nervosa was allowed to refuse feeding and start hospice.[13] What's more, these differences are not explicable according to jurisdictional variations. Clinically similar patients receiving treatment in the same geographical area are sometimes allowed to refuse artificial nutrition and die of their illness, and other times compelled to receive artificial nutrition. The law offers no consistent standard to guide clinical practice.

The ethical dilemma surrounding artificial nutrition for patients with anorexia nervosa seems irresolvable when approached as a patient autonomy question. Whether patients with anorexia nervosa are regarded as having, or lacking sufficient capacity to make an informed choice about receiving artificial nutrition, we end up with an ethically problematic outcome for the patient. The patient is either allowed to die as a direct result of their psychiatric disorder, based on the duty to respect patient autonomy, or the patient is compelled to receive treatment that they have explicitly stated they do not want, based on the argument that duties of beneficence are sufficient to justify the harms of compelling treatment. We seem to cause the patient avoidable harm no matter what treatment pathway we pursue.

This ethical dilemma is resolved, however, by reconsidering the clinical evidence for compelled artificial nutrition as an effective treatment for anorexia nervosa. Available data suggests that compelled nutrition is not, in general, an effective long-term treatment for anorexia nervosa. Many patients who undergo compelled treatment fare no better than those whose refusals are respected, and compelling treatment in the most severe cases often serves solely to extend the duration of the patient's illness as well as their length of hospital stay.[14-16]

While involuntary treatment may extend life, there is potential for it to undermine the goal of treatment as well. Many patients whose autonomy has been ignored may feel an even greater loss of control and utilize extreme measures to return to their former weight following hospital discharge.[17] A patient who undergoes involuntary treatment may be sent home at a safer and healthier weight, only to have been advanced further down the spectrum of severity of illness in order to accomplish this short-term goal.

Treatment outcomes for patients with anorexia nervosa are largely unaffected by whether compelled feeding is part of the patient's treatment plan, as studies have shown the mortality rate is lower in patients treated voluntarily and patients themselves have identified the element of control and willing participation to be essential in their treatment.[14, 18] Clinical evidence shows that compelled artificial nutrition is not generally an effective treatment for anorexia nervosa, so it should not be considered as a viable treatment option, except in circumstances when the patient's mental status is obviously clouded by the medical complications of malnutrition. In these limited cases, artificial nutrition is a trial of therapy intended to correct the patient's metabolic encephalopathy, thereby restoring the patient's decision-making capacity. Once this goal is achieved, the ethical rationale for compelling nutrition largely fades away. In the majority of cases, patients with anorexia nervosa should receive artificial nutrition only if they agree to do so.

One can make a case for, or against the patient with anorexia nervosa having the capacity for autonomous choice. However, by evaluating the clinical benefits of compelled artificial nutrition for these patients, the ethically appropriate treatment pathway becomes apparent. Compelled feeding should not be pursued for the majority of patients with anorexia nervosa because it is not an effective treatment for the disorder, and the harms of compelling treatment are therefore not counterbalanced by a corresponding benefit for the patient. The role of compelled nutrition is limited to patients for whom metabolic encephalopathy leading to incapacitation is a complication of their disorder. Outside this very limited application, we should not compel feeding for patients with anorexia nervosa.

AUTHORS

Eli Weber, PhD, MA, HEC-C is Bioethics Director for Kaiser Permanente, San Bernardino County Area. He completed his PhD at Bowling Green State University, and trained as a Clinical Ethics Fellow at the University of Texas, MD Anderson Cancer Center. His work in bioethics has appeared in *Bioethics*, JAMA *Journal of Ethics, Narrative Inquiry in Bioethics*, *the Hastings Center Report*, and other leading publications in the field.

Jo Everett, MD is an adult psychiatrist at Loma Linda University. Clinically, Dr. Everett focuses on eating disorder treatment and perinatal psychiatry. She completed her medical training at Loma Linda University and her Psychiatry residency at Southern California Kaiser Permanente.

REFERENCES

1. "Feeding and Eating Disorders." *Diagnostic and Statistical Manual of Mental Disorders Fifth Edition*, American Psychiatric Publishing, 2013, pp 338-345.

2. NIMH » Eating Disorders (nih.gov)

3. Thomas J et al. Patients with an Eating Disorder. In: T Stern, O Freudenreich, F Smith, G Fricchione, and J Rosenbaum, eds. *Massachusetts General Hospital Handbook of General Hospital Psychiatry* (7th edition). Elsevier, 2017: 177-187.

4. Skowronska A, Sojta K, Strzelecki D. Refeeding syndrome as treatment complication of anorexia nervosa. *Psychiatr Pol.* 2019; 53(5): 1113-1123.

5. Appelbaum, Paul S., and Thomas Grisso. "Assessing patients' capacities to consent to treatment." *New England Journal of Medicine* 319, no. 25 (1988): 1635-1638.

6. Beauchamp, Tom L., and James F. Childress. *Principles of biomedical ethics.* Oxford University Press, USA, 2001.

7. Tan JO, Hope T, Stewart A, Fitzpatrick R. Competence to make treatment decisions in anorexia nervosa: thinking processes and values. *Philosophy, psychiatry, & psychology: PPP*. 2006 Dec;13(4):267.

8. Charland LC. Ethical and conceptual issues in eating disorders. *Current Opinion in Psychiatry.* 2013 Nov 1;26(6):562-5.

9. Westmoreland P, Johnson C, Stafford M, Martinez R, Mehler PS. Involuntary Treatment of Patients with Life-Threatening Anorexia Nervosa. *The Journal of the American Academy of Psychiatry and the Law*. 2017 Dec 1;45(4):419-25.

10. Holm JS, et al. Reflections on involuntary treatment in the prevention of fatal anorexia nervosa: a review of five cases. *Int J Eat Disord*. 2012; 45:93-100.

11. Hebert PC, Weingarten MA. The ethics of forced feeding in anorexia nervosa. *Canadian Medical Association Journal.* 1991; 144(2):141-144.

12. Thiels C. Forced treatment of patients with anorexia. *Current Opinion in Psychiatry.* 2008 Sep 1;21 (5):495-8.

13. Jackson JZ. A case note regarding force-feeding of anorexic patients and the right to die. *MDAdvisor,* Fall 2017.

14. Russell GF. Involuntary treatment in anorexia nervosa. *Psychiatr Clin North Am.* 2001 Jun;24(2)337-49.

15. Watson T.L., Bowers W.A., Andersen A.E. Involuntary treatment of eating disorders. *American Journal of Psychiatry*. 2000;157(11):1806–1810.

16. Ramsay R., Ward A., Treasure J., Russell G.F.M. Compulsory treatment in anorexia nervosa. *British Journal of Psychiatry*. 1999;175:147–153.

17. Matusek JA, Wright MO. Ethical dilemmas in treating clients with eating disorders: A review and application of an integrative ethical decision-making model. *Eur Eat Disord Rev.* 2010;18(6):434-52.

18. Hope T, Tan J, Stewart A, Fitzpatrick R. Anorexia nervosa and the language of authenticity. *Hastings Center Report.* 41; 6(2011): 19-29.

IN PRACTICE

End-Stage Surgical Status After Repeated Foreign Body Ingestion: A Clinical Case Report

Madison S. McCarthy and Thomas A. Bledsoe, MD

Case Complexity: 1 2 3 **4**

Abstract

Repeated foreign body ingestion is common in patients with Borderline Personality Disorder (BPD).[1] The treatment of foreign body ingestion in these patients has historically been challenging given the nature of repeated ingestion and limited treatment options, yet end-stage surgical status as a result of repeated ingestion in this psychiatric condition is less common and all the more challenging to treat.[2] In this case, we report on a clinical ethics consultation in which a 40-year-old patient with Borderline Personality Disorder and an extensive history of repeated foreign body ingestion presents after ingesting 10 nails and is determined to have the prognostic status of being both end-stage psychiatrically and end-stage surgically. End-stage, in the context of this case report, is when a patient no longer has elective or emergent medical interventions as an available option of treatment. Particularly, we focus on the novelty of end-stage surgical status in Borderline Personality Disorder and discuss the ethical tension in determining a patient to be end-stage psychiatrically and the provider associated distress with no longer being able to offer medical treatment options. Based on the framework of the case, we also provide general ethical recommendations for managing patients with a lack of medical options secondary to psychiatric disease.

PRESENTATION

Ms. Smith is a 40-year-old patient with an extensive history of ingesting foreign bodies secondary to Borderline Personality disorder, Post-Traumatic Stress disorder, and Impulse Control disorder presented to the emergency department at an urban tertiary-care hospital upon referral by her primary care provider after another ingestion.

Ms. Smith has a decades-long history of psychiatric illness, which has been documented extensively in her medical record since 2001. She has an estimated >100 psychiatric-related admissions with a majority of them being related to foreign body ingestion. Ms. Smith has also had over 35 surgical procedures since 2015.

Of note, Ms. Smith has had a varied history of suicidality. For example, in 2018, it was documented that the patient ingested pills and was actively attempting to obstruct treatment in hopes of taking her own life. In 2021, the patient had two significant ingestions, although neither were reported by the patient to be a result of suicidal behavior. The second ingestion was attributed to being triggered by depression, whereas the first admission was not documented to be attributed to a specific event.

When Ms. Smith was admitted in 2021, she was sent to the emergency department by her primary care provider (PCP) after reporting severe abdominal pain and nausea without vomiting. Upon presenting to a local hospital, she was transferred to a higher level of care given her acuity. Ms. Smith did not have any notable stressors, although she reported to not feel like herself and to have skipped two days of medication. After going to the emergency department following her PCP's recommendation, a foreign body ingestion of 10 nails that had occurred 9 days prior was discovered, and the patient was subsequently admitted to an internal medicine service.

Diagnostic imaging revealed the 10 nails located within the small bowel loops of the abdomen, at least one in the duodenum, and an unspecified number in the jejunal loops of the left abdomen. Gastroenterology planned to only endoscopically intervene on the patient if nails appeared in the duodenum. A repeat CT scan showed that the nails had migrated towards the duodenum and the patient subsequently underwent an esophagogastroduodenoscopy (EGD) for retrieval. Two nails were identified in the proximal second portion of the duodenum, which left behind two 2mm lesions and distally, a 5mm linear ulceration.

The surgical and psychiatric services were also consulted. Upon initial evaluation, the surgical team signed-off on the patient, citing that "given the multiple operations this patient has required in the past for ingested foreign bodies, she has a hostile abdomen that even if an operative intervention were warranted would likely carry with it risks that outweighed the benefit. As such, this patient is no longer a surgical candidate whatsoever as there is no surgical intervention that would prove beneficial either now or in future occurrences of ingested foreign body."

At one point during the admission, a senior attending, who had operated on Ms. Smith several times previously, wrote a longer note detailing the thought process that resulted in eventually declaring this patient to no longer be a surgical candidate. Given the degree of risk of another open abdominal procedure, the senior surgeon was saddened by her condition but interestingly, not ethically conflicted in his decision to not offer another procedure and to actively recommend against such an intervention by another surgeon at their, or another, institution.

Of all the consulting providers, the psychiatry service had the benefit of knowing Ms. Smith for the longest amount of time. The service noted that she had already seen a variety of providers and undergone treatments spanning over two decades, none of which had resulted in any notable remission from repeated foreign body ingestion, therefore perpetuating the eventual state of her lesion-filled abdomen. The patient was agitated and uncooperative for the majority of her admission. However, she was deemed by the psychiatry service to have full decision-making capacity.

ETHICAL ISSUES

The clinical ethics consultation was requested primarily to evaluate the ethical implications and defensibility of not offering further surgical treatment options given Ms. Smith's repeated ingestions and overall state of her abdomen. Furthermore, the ethics consultation also helped to evaluate future psychiatric recommendations for the patient given the patient's history and the determination of limited treatment options. Although several services consulted on this patient's case, these questions were best explored through the intersection of the primary medical team's decision-making with the psychiatric and surgical services' decision making. The psychiatry service had confidence in their decision to consider this patient end-stage as a result of her repeated ingestions, which resulted in her end-stage surgical status. Similarly, the surgical service also had confidence in their decision to declare this patient to no longer be a candidate for surgical intervention. The ethics consult allowed for both the Committee and the providers to discuss the basis behind declaring this patient to be end-stage, and as a result, the lack of treatment options that follow such a declaration.

The moral distress that was most present in this consult was felt most acutely by the primary medical team. The lack of surgical options and advanced treatment options from this service and consulting services — in combination with the patient's relative youth and otherwise excellent health — was a source of significant distress.

To avoid further moral distress, the primary medical team strongly considered recommending the patient to seek care at another hospital, despite a senior surgeon consulting on this case actively discouraging intervention at another institution. The ethical node of whether or not recommending a patient to seek treatment at another hospital is appropriate, especially in the case of a patient deemed to have end-stage status, formed as a result of this distress and was the second issue discussed during this consult.

RECOMMENDATIONS

1. Declaring a patient to be end-stage status — and thus no longer a candidate for most medical interventions — is a tough decision, especially in the context of a middle-aged patient that is well-appearing. But, ultimately, this decision is at the discretion of the treatment team (s) and was rooted in what is medically indicated for the patient. The considerable surgical and psychiatric history that Ms. Smith had was well understood by the services and with the past and present circumstances in mind, we determined that such a declaration would be ethically appropriate.

2. Given limited treatment options and risk of death from perforation and other associated gastroenterological complications, the Ethics Committee suggested that the team consider referring the patient to a hospice care service. Upon further investigation, it was found that the patient could not be transferred to inpatient hospice care due to the ambiguity surrounding the patient's remaining life and overall lack of need for comfort measures given her overall feeling of wellness. The patient was also apathetic towards engaging in treatment including, but not limited to, palliative care or hospice care. The Committee recommended that the patient, in the absence of being followed by palliative care, be counseled to have a plan for palliative care services. If she was made acutely ill from complications of this most recent ingestion, the primary medical team hoped to consult palliative care to make them aware of the patient prior to this event in order to better facilitate care and reduce potential secondary moral injury.

3. The Committee advised against the primary medical team's desire to recommend that the patient present to another hospital given that it is unethical to defer a patient to seek emergent and/or inpatient-level care at another institution, especially when that care can be provided at the institution at which the patient is currently admitted.

REASONING

The Committee, much like the care team, found this case to be a challenging one given the competing ethical issues and lack of precedence. In 2014, only 15 case reports on deliberate foreign body ingestion in patients with personality disorders were found in the literature.[3] Yet, around 1500 patients die each year due to foreign body ingestion, of which 92% are estimated to be deliberate.[4] The recommendations were generated as a result of the facts given by the consortium of the treatment team, but in establishing them, we recognized and appreciated the burden held by the four treatment services involved in this patient's care.

The first recommendation, which was to determine the patient to be end-stage status, was the result of the evaluation of the patient's past medical history in the present circumstances. In the case of this patient, medical intervention was deemed to no longer be helpful to the patient, only harmful. Given that Ms. Smith was relatively well-appearing, despite the presence of foreign bodies in her abdomen, there was no other significant, medically indicated intervention other than surgery to retrieve the foreign bodies. However, her past medical history and known state of her abdomen made this not possible. Given this, the medical team's recommendation of declaring this patient to be of end-stage status was deemed ethically appropriate. The Committee recognized that the difficulty around this decision stemmed primarily from provider-associated moral distress.

The second recommendation, to introduce the patient to the palliative care team, was considered out of the norm of traditional inpatient medical practice. Often, clinical medicine tends to focus on therapeutic care and not palliation, which made this an unusual course of action. However, given the patient's unusual situation and imminent demise, the Committee felt that a palliative approach for her end-of-life care was the most ethical course of action for the patient.

The third recommendation required further clarification from the care team prior to evaluating its ethical appropriateness. The Committee felt that there were different ethical implications for telling the patient to seek care elsewhere in an emergency versus to gain a non-emergent second opinion, and therefore, asked the medical team's reasoning for wanting to recommend that the patient seek care at another hospital. In the case of this team, they hoped to advise the patient to seek care at another hospital in an emergent circumstance, which we felt as unethical.

This consult, unlike the majority of others seen by this particular Committee, was mostly about managing and evaluating the moral distress experienced by the providers taking care of this patient than the patient's own distress. Of note, this patient was not part of any committee-related ethical discussion, which made any direct discussion with the patient challenging. In the spirit of offering support, the Committee reviewed the ethical implications of the treatment team's medical recommendations, which ultimately led to reassuring the treatment team that their decisions were ethically appropriate, despite their challenging nature.

The patient, although not present for the consult, was seemingly accepting of the Committee's recommendations. She did not appear to be in distress following the consult.

In emergency department encounters following this admission and the ethics consult, she has declared herself to be DNR/DNI and has even offered to discuss the recommendations of this consult to her providers.

AUTHORS

Madison S. McCarthy is a student at Brown University studying Human Biology and Medical Anthropology. She has served as an appointed member of the Rhode Island Hospital Ethics Committee since September 2020. Her research interests include surgery, bioethics, and health policy and services research. She has been awarded research fellowships at Brown University and Weill Cornell to investigate these interests. She is currently at Stanford University School of Medicine where she is working with the Department of Surgery on outcomes research and clinical trials.

Thomas A. Bledsoe, MD is a general internist with Brown Medicine in Providence, Rhode Island. He is a former Regent of the American College of Physicians and past Chair of the College's Ethics, Professionalism and Human Rights. At Brown, he is a Clinical Associate Professor of Medicine and has been primarily responsible for clinical ethics education at Brown and is the Chair of the Rhode Island Hospital Ethics Committee.

REFERENCES

1. Navinés R, Gutierrez F, Arranz B, et al. Long-term and bizarre self-injurious behavior: an approach to underlying psychological mechanisms and management. *J Psychiatr Pract*. 2013;19(1):65-71. doi:10.1097/01.pra.0000426329.34149.b6

2. Gitlin DF, Caplan JP, Rogers MP, Avni-Barron O, Braun I, Barsky AJ. Foreign-body ingestion in patients with personality disorders. *Psychosomatics.* 2007;48 (2):162-166. doi:10.1176/appi.psy.48.2.162

3. Management of a cluster of foreign body ingestion incidents in patients with borderline personality disorder. Dyke J, Hendry K, Hill J, Schultz M, Mason E, Glue P. *Open J Psychiatry.* 2014;4:99–103

4. Poynter BA, Hunter JJ, Coverdale JH, Kempinsky CA. Hard to swallow: a systematic review of deliberate foreign body ingestion. *Gen Hosp Psychiatry.* 2011;33 (5):518-524. doi:10.1016/j.genhosppsych.2011.06.011

Discharge and Just Access When Experiencing Homelessness

The Editorial Group of the Lynch Center for Ethics

Case Complexity: 1 **2** 3 4

Abstract

Because discharge planning is likely to go much more slowly for a debilitated patient experiencing homelessness who is uninsured than a well-insured patient, a question of just access arises in the context of a patient being deprived of the physical therapy services he needs simply because of his homeless status. Medical respite for those experiencing homelessness is defined by the United States (US) standards setting organization, the National Health Care for the Homeless Council (NHCHC), as "… acute and post-acute medical care for those experiencing homelessness who are too ill or frail to recover from a physical illness or injury on the street or in a shelter but are not ill enough to stay in the hospital."[1] Medical respite for those experiencing homelessness is not only good medicine for patients but it provides considerable benefits to the hospital. Medical respite discharges save hospitals on excessive length of stays and reduced readmissions.[2-6]

PRESENTATION

Mr. L is 51 years old. Two weeks ago, he presented to the emergency department with acute stomach pain. He was found to have a large kidney stone blocking his urinary tract. Because of his infection and fever, his kidney stone, which was assessed as too large to pass, could not be surgically removed at the time of his presentation to the emergency department. Rather, he was admitted, and a stent was placed to allow for urinary flow until the patient became afebrile. The patient's course was complicated by an acute appendicitis on day 5 for which his appendix was removed. Unfortunately, even with antibiotic treatment, his fevers persisted for the following two weeks. Only in the past 48 hours has he been afebrile, finally allowing for removal of the kidney stone. On day 28, Mr. L was ready for discharge.

Mr. L had been experiencing homelessness prior to his admission to the hospital. Discharge planning is now attempting to discharge him back to his shelter. He was severely debilitated by his illnesses, however, and the treating team believes that after being in bed for 28 days he is too weak to be safely discharged to a shelter. Because Social Work believed that he was going to recover more quickly than he has, they did not start the necessary paperwork to obtain Medicaid for him. Because he is without insurance, it appears that there is no suitable placement.

ETHICAL ISSUES

Because discharge planning is likely to go much more slowly for a debilitated patient experiencing homelessness who is uninsured than a well-insured patient, a question of just access arises in the context of a patient being deprived of the physical therapy services he needs simply because of his homeless status. If this patient had been identified as homeless and uninsured early in his admission, paperwork to obtain Medicaid could have been submitted and his Medicaid insurance might have been obtained. That the hospital was slow to file this paperwork is not an ethically supportable reason to unsafely discharge him now.

RECOMMENDATIONS

1. Ethics recommends that the patient be provided intensive physical therapy to assure that he regains the strength needed for him to return to ambulatory clinical status.

2. Ethics recommends that social work begin the paperwork for the patient to qualify for Medicaid.

3. Ethics recommends that the patient be discharged only to a shelter that includes medical respite beds.

REASONING

That the patient receive intensive physical therapy, which acute care hospitals do not usually provide, is recommended because there is often a very small window of opportunity during which a patient has the prospect of regaining function often lost from a long, debilitating illness. Since this patient is experiencing homelessness and is not easily discharged because of his uninsured status, without the physical therapy services that insured patients regularly receive on an outpatient basis, it is incumbent upon the hospital to provide such services so that while discharge planning progresses he is able to return to his pre-hospitalization, ambulatory status.

There is, given that the hospital is in an urban area, the prospect that there are medical respite beds somewhere. A medical respite bed is likely the best placement for this patient. Although there are few such beds in this man's jurisdiction, there are some. Here again, social work plays a key role in knowing where those beds are and working diligently to secure a medical respite bed for this patient.

Medical respite for those experiencing homelessness is defined by the United States (US) standards setting organization, the National Health Care for the Homeless Council (NHCHC), as "…acute and post-acute medical care for those experiencing homelessness who are too ill or frail to recover from a physical illness or injury on the street or in a shelter but are not ill enough to stay in the hospital." [1] The NHCHC goes on to clarify that, "Medical respite care is not skilled nursing care, nursing home care, assisted living care, or a supportive housing program." It is short term (i.e., 30 -90 days) care for those ready for hospital discharge, but who have no safe place to go to receive needed medical and psychological services in order to make a recovery sufficient to utilize provided social services on their way to permanent supportive housing.

Medical respite for those experiencing homelessness is not only good medicine for patients but it provides considerable benefits to the hospital. Medical respite discharges save hospitals on excessive length of stays and reduced readmissions.[2-6] It serves everyone to be able to discharge Mr. L to a medical respite bed than to have him stay indefinitely in the acute care setting. Fortunately for Mr. L, one of the hospital's social workers was able to find him a medical respite bed in one of the city's best care for the homeless programs. In less than 36 hours, Mr. L moved from the hospital into a respite program from which, when he was ready, would transition Mr. L into supportive housing so he would not have to return to the street.

REFERENCES

1. National Health Care for the Homeless Council (NHCHC). Medical Respite Care: Financing Approaches. June, 2017. Accessed March 25, 2022. https://nhchc.org/clinical-practice/medical-respite-care/

2. DeRenzo EG. Medical respite for the homeless: Moving from the present to the future. In: EC Ritchie, Llorente MD, eds. *Clinical Management of the Homeless Patient: Social Psychiatric, and Medical Issues.* Springer Nature; 2021, 337-348.

3. Racine MW, Munson D, Gaeta JM, Baggett T. Thirty-day hospital readmission among homeless individuals with Medicaid in Massachusetts. *Med Care* 2020 Jan;58(1):27-32.

4. Shetler D, Shepard DS. Medical respite for people experiencing homelessness: Financial impacts with alternative levels of Medicaid coverage. *J Health Care Poor Underserved.* 2018; 29(2):801-813.

5. Cornes M, Whiteford M, Manthorpe J, Neale J, Byng R, Hewett N, Clark M, Kilmister A, Fuller J, AldridgeR, Tinelli M. Improving hospital discharge arrangements for people who are homeless: a realist sysnthesis of the intermediate care literature. *Health Soc Care Community.* 2018 May; 26(3): e345-e359.

6. Bauer J, Moughamian A, Viloria J, Schneidermann M. Leaving before discharge from a homeless Medical Respite program: Predisposing factors and impact on selected outcomes. *J Health Care Poor Underserved*. 2012 Aug; 23(3):1092-105.

Treatment Refusal When Lacking Capacity

The Editorial Group of the Lynch Center for Ethics

Case Complexity: 1 2 **3** 4

Abstract

Although there is some controversy in the ethics community about whether capacity should be assessed on a sliding scale,[3] there is agreement that capacity is assessed in relation to a specific question or decision to be made. Some have gone as far as to suggest that when a patient refuses to explain his or her reasons for treatment refusal and a physician cannot make a capacity assessment, that refusal should be honored.[4] On what casuistic and/or rational basis, then, might a refusal of recommended intervention be accepted when the refusal comes from a patient who lacks capacity, either by assessment or presumption?

PRESENTATION

Mrs. D is an 83-year-old patient who came into the hospital's emergency department after a fall. She had broken her hip and went directly into corrective surgery so she would be able to walk again. While performing the hip surgery the physicians found what they believed to be cancer of the bladder. Prior to the fall, Mrs. D was her own decision maker. Once out of surgery she was delirious and had reverted to speaking her native Italian. She was assessed as lacking decisional capacity.

For the last several years, since she was widowed, Mrs. D has lived with her 80-year-old brother and 78-year-old sister in Albany, New York. Although both of the patient's siblings felt that she should move into her son's home and receive cancer treatment there, the physicians believed she required too much care to recuperate at home. In addition to the physical therapy needed to recover from the hip, the patient had become incontinent and continued to be delirious. The patient's son, who held Mrs. D's Durable Power of Attorney, flew to New York when his mother was ready to travel and brought her by ambulance to a community rehabilitation and nursing facility in North Carolina, 5 minutes from his home.

Once settled in North Carolina, the patient's son and daughter-in-law had the patient seen by a geropsychiatrist who cleared the delirium sufficiently to return the patient to speaking English. After a couple weeks, she was able to understand that her son was going to make the big decisions for her; she never was able to regain her decision making capacity. Nevertheless, she was able to carry-on a short conversation with her son each day when he arrived. She would smile and say how happy she was to see him.

Although feeling the pressure from his uncle and aunt to get his mother fully diagnosed and treated for any malignancy, the son did not believe his mother would want to be treated for the cancer, if that's what it was. Also, he felt she could understand simple questions about her future care. He thought he knew what she would and would not want but also wanted to involve her to the greatest degree reasonable, in decisions of life and death. She had always been an independent thinker.

He asked her if she had cancer, would she want to be treated. Mrs. D's reply was, "Absolutely not." Over a period of several days, the son asked the same question in different ways and consistently received the same answer. When the son tried to explain this to his uncle and aunt, they objected and insisted the son get his mother fully diagnosed and treated for any cancer. Given that the son was the patient's designated surrogate decision maker and not her siblings, treatment was never forced on the patient.

The siblings kept calling the facility and making hateful comments about the son to the hospice care team.. The facility referred the case to its ethics committee. The chair of the ethics committee, a community geriatrician, meets with the resident, and then with the son. Her recommendations are as follows.

RECOMMENDATIONS

1. The ethics committee recommends that all calls from these siblings be referred to the appropriate surrogate, i.e., her son.

2. The ethics committee recommends that not pursuing a definitive cancer diagnosis and treatment for the putative bladder cancer is ethically supportable because:

a. Diagnostics and/or treatment could be noxious for the patient without the patient appreciating the reason for being submitted to such noxious interventions.

b. Although the patient lacks decisional capacity, she appears to understand enough to refuse, and her refusal should be honored.

REASONING

It is well-established in ethics and the law that having decisional capacity is the cornerstone of informed consent or informed refusal.[1] The four standard ethics and legal criteria for having decisional capacity are that the individual must be able to:

1. Express a choice,
2. Understand the information provided,
3. Appreciate the implications of the information for one's own situation, and
4. Reason coherently in reaching a decision.[2]

Although there is some controversy in the ethics community about whether capacity should be assessed on a sliding scale, there is agreement that capacity is assessed in relation to a specific question or decision to be made.[3] Some have gone as far as to suggest that when a patient refuses to explain his or her reasons for treatment refusal and a physician cannot make a capacity assessment, even under these circumstances a refusal should be honored. [4]

On what basis, then, might a refusal of recommended intervention be accepted when the refusal comes from a patient who lacks capacity, either by assessment or presumption? The "reasonable person" is commonly referred to in legal contexts as a hypothetical individual who approaches a situation with an appropriate caution and then acts. Thus, the "reasonable person" is a legal fiction created to elucidate what a reasonable individual might decide to do, or not do.

In considering the "reasonable person standard," one could apply the notion to evaluate the refusal of a patient lacking capacity in comparison to what the "reasonable person" might decide about cancer treatment when situated similarly to Mrs. D. In Mrs. D's case, one might ask, "How does her refusal to undergo potentially invasive and/or noxious diagnostics and/or treatment for her putative bladder cancer compare to what the reasonable person might choose?" At the age of 83, she repeatedly says that she never wants to "… go back to that place with all those doctors and nurses who ask you a lot of questions, poke you all the time, and won't let you sleep…" Given this, refusing potentially invasive and/or noxious cancer diagnostics and/or treatment appears a reasonable choice.

Although Mrs. D is not as impaired as Joseph Saikewicz was in the case of Superintendent of Belchertown State School and another vs Joseph Saikewicz, July, 1976 – November, 1977, this classic case in the development of case law and ethics around medical care of patients lacking capacity serves as a useful analogy. In the Saikewicz case, Joseph Saikewicz was a severely cognitively impaired, 67-year-old with an IQ of 10 and an approximate mental age similar to that of a two-year-old child. In otherwise strong health, Mr. Saikewicz was found to have acute myeloblastic monocytic leaukemia. On his behalf, the school superintendent and a staff attorney petitioned the court to appoint a guardian. Simultaneously, they petitioned the court that an attorney ad litem be appointed for purposes of getting Mr. Saikewicz treated. Instead, the attorney ad litem recommended that Mr. Saikewicz not be treated. This recommendation was based on a standard risk/benefit analysis.[5]

Any clinical ethicist involved in end-of-life cases ought to be familiar with this classic case. This case has helped guide decision-making associated with the ethics of end-of-life for patients lacking capacity since it was decided.

In Mrs. D's case, she is far less cognitively impaired than was Mr. Saikewicz. She is able to express her preferences and they are grounded in her immediately lived experience. Even though her bladder cancer is not yet diagnosed, even the diagnostic procedures needed to make such a determination would require her to be sent to the hospital, or at a minimum to a physician's office. The distress of forcing her to agree to such interventions might, in and of itself, make the effort more burdensome than would be reasonable for Mrs. D. Finally, given what the physicians saw when they were doing the scans required to fix Mrs. D's hip, they believe that the bladder cancer has progressed into the bladder wall and has likely metastasized, which makes for a grimmer prognosis, regardless of intervention. As such, it is not an unreasonable decision to forgo definitive diagnostics and/or curative intervention and, instead, enter hospice, which will only focus on her comfort. Thus, even though she is not a fully capacitated decision maker, her son feels that her refusal is consistent with what she would have decided, were she fully capacitated, and that she is making a reasonable decision that should be honored.

Even though Mrs. D's siblings kept up their abusive calls until she died, her son took solace knowing that he did not force medical treatments on his mother, which she adamantly refused. He felt good that he had been able to share with her almost a full year of daily visits, and that she died comfortably and peacefully in her sleep.

REFERENCES

1. Faden RR, Beauchamp TL, in collaboration with King NMP. *A History and Theory of Informed Consent. 1986.* Oxford University Press: NY.

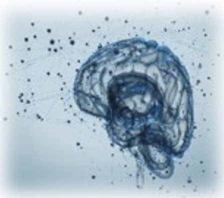
2. Appelbaum PS. Clinical practice: Assessment of patients' competence to consent to treatment. *N Engl J Med.* 2007 Nov 1;357(18):1834-40.

3. Howe E, Ethical aspects of evaluating a patient's mental capacity. *Psychiatry* (Edgmont). 2009 Jul;6 (7):15-23.

4. Hurst SA. When patients refuse assessment of decision-making capacity: How should clinicians respond? *Arch Intern Med.* 2004;164:1757-760.

5. Nicolosi GG. Joseph Saikewicz revisited. *America (NY)* 1978 apr 15;138(14):293.

PROGRAM FOR NEUROETHICS AND CLINICAL CONSCIOUSNESS



The PNCC was established in 2019 as a small research program devoted to the intersections of philosophy, neuroscience, empirical psychology, and clinical neurology. The PNCC serves as a special research unit of the Lynch Center by contributing to relevant policy and practice, including specialized ethical analyses of clinical cases involving neurointensive or psychiatric care. In addition, the PNCC invites scholars of relevant disciplinary backgrounds and at various degrees of professionalization to collaborate in investigating the ontological and normative clinical implications of ongoing advances within these fields.

We are pleased to present here the peer-reviewed work of the Lynch Center's most recent PNCC Visiting Scholar, Jada Wiggleton-Little, a doctoral candidate in the Department of Philosophy at University of California, San Diego (UCSD). Her current areas of interest are the intersection of chronic pain and language, particularly in the context of pain management disparities. Wiggleton-Little has completed a Ph.D. Student Summer Funding Fellowship with UCSD's Institute of Practical Ethics, was a Ford Foundation Predoctoral Fellowship recipient, and was selected as a Sadler Scholar with the Hastings Center.

Regards,

Christian Carrozzo, PhD (c)

Founder, Program for Neuroethics & Clinical Consciousness (PNCC)
Managing Editor, *Journal of Hospital Ethics*
John J. Lynch, MD Center for Ethics

MPQ Descriptors as a Pain Pidgin Language

Jada Wiggleton-Little, PhD (c)

Abstract

Philosophers have long noted a non-translatable difference between medical "pain-talk" and every day "pain-talk." Yet, for the shared goal of coordinating care, patients exchange their subjective experiences for an appropriate diagnosis-treatment pairing despite patients and clinicians occupying radically different perspectives toward pain. Verbal pain descriptors, such as those found in the McGill Pain Questionnaire (MPQ), seem to foster this coordination by operating as a pain exchange or pidgin language. An exchange language emerges in a trading zone and allows a rather superficial description of an object to be successfully communicated, at the expense of precisely capturing either perspective. Using a Galisonian' trading zone framework, I argue that MPQ descriptors operate as an exchange language due to the descriptors' ability to express otherwise private, subjective experiences of pain in a way that often maps onto physiological mechanisms. By adopting a Galisonian approach, we see that coordination best explains the effectiveness of the MPQ descriptors, their limits, and the harms that will ensue if medicine is overly confident of the coordination power of these pain descriptors.

Introduction

Philosophers have long noted a pain communication barrier based on the difference between medical "pain talk," i.e., indicative of specific biological markers, physiological mechanisms, and treatment targets, and everyday "pain talk," i.e., as descriptions of pain in terms of the first-person experience.[1] Talk of biological markers and physiological mechanisms is more likely to be found in scientific theories of pain, but given the clinic is moving toward a mechanism-based approach to diagnosing and managing chronic pain, I will collapse science with medical "pain talk." The pain lexicon commonly used in the clinical setting includes such verbal descriptors as numb or stabbing. These descriptors are significant for expressing otherwise private, subjective experiences of pain in a way that often maps onto physiological mechanisms, making the descriptors diagnostically valuable for the clinician. This appears especially to be the case with the sort of descriptors found in the McGill Pain Questionnaire (MPQ), which seem to cross this communication barrier by operating as a pain exchange or pidgin language.

A trading zone is an exchange region where members of distinct cultures would meet and trade. In a trading zone, what gets communicated is a relatively superficial description of the traded object, a thin description that fails to fully translate the significance or value of the object for either community yet is still valuable for its ability to foster coordination.[2] Peter Galison used a trading zone framework to capture the local exchanges between distinct scientific communities— i.e., engineers, experimenters, and theorists—that still occurred during Kuhnian paradigmatic shifts in science. Despite incommensurable differences in language *globally,* like in other reported trading zones, experimenters and theorists established a contact language for *local* coordination. Even though objects carry radically different classifications and significance between experimenters and theorists, these groups collaborate toward a shared goal of knowledge production by coming to a consensus about the means of the exchange.

Despite occupying radically different perspectives toward pain, patients and clinicians, too, trade pain information (e.g., a symptomatic report for an associated treatment or diagnosis) to coordinate toward a shared goal of care and pain relief. On a global scale, language has grave limitations as a means of pain assessment. There are inevitable translational failures between how the patient subjectively experiences pain and how the clinician can objectively investigate pain. One, subjective pain experiences fail to fully translate to verbal language, given experiences of pain resist framing in ordinary language, cannot be shared, and are assertedly inaccessible to others.[3,4] But, bypassing this, patients and clinicians also place a different meaning and value on pain. Every day "pain-talk" refers to neither a treatment target nor a biological marker of pain, the specifications of which are seemingly essential to pain science and medicine.[5] The concerns of everyday life are whether the person is in pain, while the concerns of science and medicine are whether specific pain interventions ought to be made and how. These are non -translatable vantage points of what is being discussed. Philosopher Daniel Dennett has gone as far as to argue that the subjective, everyday talk of pain cannot be interpreted in terms of the scientific, medical value of pain without changing the subject matter entirely.[6]

By adopting a trading zone framework for pain communication, we can see how MPQ fosters coordination despite these global differences as a pain exchange language. Moreover, a trading zone framework is also helpful in illuminating the harms that can ensure when we mistakenly treat this pain exchange language as a *direct translation.*

MPQ Descriptors as an Assessment Tool

The MPQ is the first systematic attempt to incorporate verbal descriptors in pain assessment. Currently, it is still the most popular multidimensional tool to elicit verbal pain language from patients.

In 1971, Robert Melzack created the MPQ to address the inadequacy of the prevailing pain vocabulary being used in the clinic at the time. This vocabulary captured only the intensity of a pain experience.[7] According to Melzack, describing pain only in terms of intensity was an exceptionally poor way to capture the multidimensionality of a patient's pain experience. The MPQ is a categorical scale that consists of 78 pain descriptors into 20 subcategories and is organized into four broader categories (*sensory, affective, evaluative, and miscellaneous*); it also features a numerical ranking to capture the intensity dimension of pain. Later, in 1987, the short-form McGill Pain Questionnaire (SF-MPQ) was developed, consisting of only 15 descriptors (11 sensory; 4 affective) which are each rated on an intensity scale.[8]

In reflecting on the development of the MPQ, Melzack noted how patients with “tabes dorsalis, reflex sympathetic dystrophy, back pains, and so forth” would describe their pains in vivid detail using a rich vocabulary.[9] He then tracked a pattern between patients with a particular pain syndrome and the different pain descriptors expressed. For example, when deciding between trigeminal neuralgia and atypical facial pain, the sole use of MPQ descriptors was 91% successful in matching a patient to an appropriate diagnosis.[10] Patients with trigeminal neuralgia tended to choose flashing, *terrifying, blinding, and torturing*, while patients with atypical facial pain tended to choose vicious*, diffuse, and excruciating*. When using the MPQ, patients are directed to select the pain descriptors that *best* describe their subjective pain experience. These descriptors might not be a natural language generated by patients but are one in which patients are "grateful" to be provided given the terms facilitate some description of patients' pain and save patients from having to search for words to communicate with clinicians.[11,12] Even if MPQ descriptors do not perfectly match the common vocabulary patients use when talking about their pain in everyday life, these descriptors can reflect statistically significant disease patterns and can be used to identify underlying pain mechanisms characteristic of different types of pain conditions and disorders.

Thus, MPQ descriptors are primarily expressively valuable to patients and are primarily differentially valuable to the clinician. Moreover, they constitute the phenomenon of pain into a "workable object."[13] MPQ descriptors seemingly give patients and clinicians a shared language that both expresses an otherwise private and inexplicable experience, albeit with a superficial description of the experience, and pins down this description for diagnosis and treatment purposes. For this reason, some refer to the creation of the MPQ as a “translation exercise,” one in which the multidimensional nature of pain was translated into sensory and affective descriptors.[14] Proof of this "translation" is supposedly evident by laypeople's endorsement and ranking of these pain descriptors. The fact that these descriptors were also able to identify underlying pain mechanisms was an additional, less explicit objective of creating the MPQ.

Despite being praised for turning the multidimensional facets of pain into a workable object, MPQ descriptors have severe limitations. Studies suggest that laypeople whose first language is English find difficulties using the elicit language. One study suggests that 40% of the MPQ descriptors were incomprehensible, underused, or their use was ambiguous.[15] Other studies have shown that the MPQ descriptors have limited discriminatory power for making diagnostic differentials, with differences being observed in the frequency of the use of pain descriptors in different conditions and variations being observed in endorsement rates in patients with the same condition.[14] Specifically, researchers have concluded that MPQ descriptors could identify neuropathic pains, but the sensory descriptors identified differed per study.[16] These limitations suggest MPQ descriptors fail as a direct translational project; they fail to capture the full significance of a pain experience for either the patient or clinician, let alone both. This is not a problem unique to MPQ descriptors but is observed in all pain assessment tools.

MPQ Descriptors as a Pidgin Language

Trading zones are locations in which communities with a deep communication problem still manage to communicate. For a trading zone to emerge, communities had to live close enough to trade but be distinct enough in culture and traditions to be portrayed as being from "different worlds."[2] Often there was no direct translation between the different communities engaged in cultural trade. Yet, these communities could at least unite on the rules and language of the trade itself, despite the goods being traded still maintaining a non-translatable meaning and value within the borders of each community. Galison refers to this emergent language of the trade as the exchange or *pidgin* language.

Pidgin languages are learned as a second language, and their function is to provide coordination in the trading zone. Galison writes:

> *What is crucial is that the two groups can collaborate in the local context of the trading zone, despite the differences in classification, significance, and standards of demonstration. They can come to a consensus about the procedure of exchange, about the mechanisms to determine when goods are "equal" to another.*[2]

This coordination is achieved because the *pidgin* language provides a superficial, *thin* description of the traded goods. By thin, Galison means there is no reference to a universal value assigned to the traded good; it bypasses the presupposition that there is any consensus among those engaging in the trade about the full significance (*or thick description*) of what is being traded. The meaning and historic-situatedness of the trade object get stripped away, the rules of the trade shift to a more regularized use, and what is then left to be interpreted is the exchangeability of the object.

For example, consider the trade observed between the peasant and landowning classes that resided in Cauco Valley, in Colombia.[2] For the peasant class, money had moral value and was used in ritual practices such as the secret baptism of money by godparents. In contrast, money was value-neutral and significant only in establishing further wealth for the landowning class. In the trading zone, both classes left behind the culturally laden value and meaning of money unique to their community and agreed on the exchangeability of land for money. The spiritual value of money could not and need not be perfectly translated to the value of a piece of land.

Similarly, MPQ descriptors cross the language barrier between everyday first-person, subjective reports and the technical terminology of diagnostic medicine not by translation but by *coordination*. Analogously, I take it that the MPQ questionnaire functions much like a trading zone, and the MPQ descriptors as the pidgin language. The MPQ serves as a communicative floor where patients can exchange their subjective experiences for an appropriate diagnosis-treatment pairing. Patients and clinicians have agreed to the rules of the MPQ and its regularized use in the clinic. The exchange language, the MPQ descriptors, strips away facets of the complex, phenomenological experience of pain, leaving behind a 'pain' that can be interpreted by a clinician for its exchangeability with a clinically indicated pain intervention.

However, patients will report their experiences of pain via a pain descriptor for the value of communicating that subjective experience, and the descriptors were not meant by the patient to indicate the pain mechanism activated or to request a particular pharmaceutical intervention. The clinician, trained to value 'pain' as a treatment target, comes to the communicative floor interpreting the descriptors as a sensory phenotype. For example, clinicians can interpret a patient report of a *cramping* or *squeezing* sensation as indicative of the patient experiencing visceral pain. With visceral pains, opioids are the most effective treatment. Opioids would not be the most appropriate course of treatment for, say, a patient reporting an *achy* or *throbbing* sensation, descriptors that the clinician may interpret as the patient experiencing somatic pain.[17]

Coordination Has its Limits

There are payoffs for adopting a trading zone framework: by shifting our attention to the localized pain exchanges that still occur between a patient and clinician, we see that coordination best explains the effectiveness of MPQ descriptors—and their limits. When medicine is overly confident of the coordination power of these pain descriptors, mistakenly treating a pain exchange language as a direct translation, vital aspects of the patient’s pain experience can be overshadowed or missed entirely by the demands to conform to a language designed to meet clinical objectives.

Galison refers to out-talk as the communication that occurs between members of different groups. It is a clinician's interpretation of a patient's out-talk of pain that results in pain care. As Galison notes, because there is no perfect translation, there will always be a compromise in out-talk.[18] Thus, the following questions often arise when discussing a pidgin language: What aspects of the groups' relationship with the traded good get left behind in these thin descriptions? What aspects of the groups' relationship with the traded good get pushed forward? In the case of MPQ descriptors, vital aspects of the patient's relevant pain experience can be overshadowed or missed entirely, and what gets pushed forward is the clinical ideal of a 'pain' that is standardized and objective.

The coordinating potential of a pidgin language can be influenced by its formation. With many exchange languages that emerge in a trading zone, it is the dominant of the two groups that most contribute to the syntax, and the marginalized group is expected to conform their unique language to meet trading needs. Within the clinical domain, patients occupy a marginalized group relative to healthcare professionals because of vulnerabilities with respect to their illness, their general servility to healthcare providers' demands, their overall lack of institutional power and epistemic authority, and their general lack of medical expertise relative to healthcare professionals within the clinical space.[19] The MPQ descriptors were developed primarily on expert opinion and fail to include descriptors patients report are the most important or common. Various online resources designed to teach patients how and why they should use these descriptors are evidence that the burden is on the patients to conform to the rules of the trade.[20]

Although patients are "relieved" at seeing these descriptors, these descriptors are metaphorical or nonexistent.[21] For instance, patients may feel that, of the descriptors provided, *gnawing* best describes their experience, but many patients have never experienced the sensation of being persistently bit by a creature. Instead, *gnawing* and other descriptors become catch-all terms: an offered sensory phenotype for what the patient may truly perceive as, say, gnawing-like pains, pains that feel drilling but also feel numb, grinding pains, etc. In other words, the one descriptor, *gnawing*, may apply to pain types with potentially significant phenomenological differences that can be interpreted for vastly different pain interventions. Yet, the current syntax persists because descriptors like *gnawing* are parsimonious and more compatible with a clinic's need for standardization compared to the countless ways individuals actually experience and may choose to express a *gnawing pain.*

It is conceivable that a patient could be harmed via a misdiagnosis or delayed treatment due to the potential overconfidence medicine has placed in verbal descriptors and their ability to coordinate pain care, especially regarding coordinating pain care for chronic pain conditions. The SF-MPQ has been proposed by the International Pelvic Pain Society to be used in the assessment of chronic pelvic pain (CPP). Cramping, aching, and hot burning as descriptors were shown to have a high negative predictive value. If a patient with CPP did not provide one of these terms, a healthcare professional could reasonably rule out the diagnoses of endometriosis, abdominal myofascial pain syndrome, and pudendal neuralgia.[22] Specifically, if a patient doesn't choose cramping to describe their pain, the chance that endometriosis is present is only 11%.[22] This has important clinical implications; an invasive laparoscopy is the only definitive diagnostic tool for endometriosis. If a patient with CPP does not choose cramping, a laparoscopy will probably not be included in an initial component of the evaluation.

Endometriosis has a diagnostic delay of 8.6 years, with 75.2% of patients reporting being misdiagnosed with another physical health or mental health problem, most frequently by gynecologists and general practitioners. Although *cramping* is a typical sensory phenotype associated with endometriosis, cramping also has low specificity (33%).[22] Many women without endometriosis are also likely to choose the term to describe their CPP. Thus, a failure to choose cramping as a descriptor could disrupt an initial investigation into an endometriosis diagnosis; yet a patient choosing cramping could also "communicate" too many diagnostic possibilities.

Pidgin Languages Evolve

In conclusion, Galison's trading zone framework also provides a helpful perspective on how we should approach MPQ descriptors going forward.

Language changes over time. An artificially created pidgin language can evolve into a native *creole* language.[24] The *creole* language still has a simpler grammar than that found in either community. Still, the new *creole* language develops a more extensive vocabulary capable of a broader range of communicative exchanges. The descriptors incorporated in the MPQ have remained unchanged since its inception despite modern language evolving outside the clinical setting. One recommendation would be to adjust the MPQ descriptors to reflect better the language of patients who are now situated in a culturally rich, more technologically advanced society. Analyzing a wide range of social media posts, researchers were able to identify novel contemporary pain descriptors that individuals naturally used to talk about their pain: *puncturing, contraction, clenching, scratching, straining, horrendous, horrifying, mild, irritating, horrible, excruciating, and distressing*.[25] These identified descriptors could provide the MPQ with stronger discrimination and coordination power. Adding these descriptors could be the first practical step in transforming the MPQ descriptors from an artificial pidgin language to a more communicatively rich language.

The clinic potentially faces a new era of a mechanism-based approach to diagnosing and managing chronic pain. For this reason, it is vital to have a clear understanding of what information can be conveyed and communicated through MPQ descriptors as a pain assessment tool. Such information may be limited but is necessary for the trade.

REFERENCES

1. Corns J. Pain eliminativism: scientific and traditional. *Synthese.* 2016;193(9):2949-2971. doi:10.1007/s11229-015-0897-8.

2. Galison P. *Image and Logic: A Material Culture of*

Microphysics. Chicago, IL: University of Chicago Press; 1997.

3. Baszanger I. *Inventing Pain Medicine: From the Laboratory to the Clinic.* New Brunswick, NJ: Rutgers University Press; 1998.

4. Scarry E. *The Body in Pain: The Making and Unmaking of the World.* New York, NY: Oxford University Press; 1985

5. Wall, PD. Response to editorial by Anand and Craig. *Pain.* 1996;67(1):209. doi:10.1016/0304-3959(96)03196-X.

6. Dennett D. *Content and Consciousness*. New York, NY: Routledge; 1986.

7. Melzack R, Togerson WS. On the language of pain. *Anesthesiology.* 1971;34(1):50-59. doi:10.1097/00000542-197101000-00017.

8. Melzack R. The short-form McGill Pain Questionnaire. *Pain.* 1987;30(2):191-197. doi:10.1016/0304-3959(87)91074-8.

9. Melzack R. The McGill pain questionnaire: From description to measurement. *Anesthesiology.* 2005;103(1):199-202. doi:10.1097/00000542-200507000-00028.

10. Melzack R, et al. Trigeminal neuralgia and atypical facial pain: Use of the McGill pain questionnaire for discrimination and diagnosis. *Pain.* 1986;27(3):297-302. doi:10.1016/0304-3959(86)90157-0.

11. Melzack R. The McGill Pain Questionnaire: Major properties and scoring methods. *Pain.* 1975;1(3):277-299. doi:10.1016;0304-3959(75)90044-5.

12. Crawford CS. From pleasure to pain: The role of the MPQ in the language of phantom limb pain. *Social Science & Medicine*. 2009;69(5):655-661. doi:10.1016/j.socscimed.2009.02.022.

13. Whelan E. Putting pain to paper: Endometriosis and the documentation of suffering. Health: *An Interdisciplinary Journal for the Social Study of Health, Illness and Medicine.* 2003;7(4):463-482. doi:10.1177/13634593030074005.

14. Main CJ. Pain assessment in context: a state of the science reveals of the McGill pain questionnaire 40 years on. *Pain.* 2016;157(7):1387-1399. doi:10.1097/j.pain.000000000000457.

15. Fernandez E, Towery S. A parsimonious set of verbal descriptors of pain sensation derived from the McGill Pain Questionnaire. *Pain.* 1996;66:31-37. doi:10.1016/0304-3959(96)02992-2.

16. Heraughty M, Ridehalgh C. Sensory descriptors which identify neuropathic pain mechanisms in low back pain: A systematic review. *Current Medical Research and Opinion.* 2020;36(10):1695-1706. doi:10.1080/03007995.2020.1790349.

17. Fink R. Pain assessment: The cornerstone to optimal pain management. Baylor University Medical Center *Proceedings.* 2000;13(3):236-239. doi:10.1080/08998280.2000.11927681.

18. Galison P. Trading with the enemy. In Gorman ME, ed. *Trading Zones and Interactional Expertise.* Boston, MA: MIT Press; 2010:22-52.

19. Freeman L, Stewart H. Microaggressions in clinical medicine. *Kennedy Institute of Ethics Journal.* 2019;28(4):411-449. doi:10.1353/ken.2018.0024.

20. Weaver T. How and why to escribe pain accurately to your doctor. Ohio State University Wexner Medical Center. https://wexnermedical.osu.edu/blog/how-and-why-to-describe-pain-accurately-to-your-doctor. Accessed January 3, 2022.

21. Hardcastle V. *The Myth of Pain.* Boston, MA: MIT Press; 1999.

22. Droz J, Howard, FM. Use of the Short-Form McGill Pain Questionnaire as a diagnostic tool in women with chronic pelvic pain. Journal of Minimally Invasive *Gynecology.* 2011;18(2):211-217. doi:10.1016/j.jmig.2010.12.009

23. Bontempo AC, Mikesell, L. Patients' perceptions of misdiagnosis of endometriosis: Results from an online national survey. *Diagnosis.* 2020;7(2):97-106. doi:10.1515/dx-2019-0020.

24. Encyclopedia Britannica, Inc. Pidgins and creoles. Encyclopedia Britannica. https://www.britannica.com/topic/language/Pidgins-and-creoles. Accessed March 2, 2022.

25. Tan M, Goh C, Tan H. Contemporary English pain descriptors as detected on social media using artificial intelligence and emotion analytics algorithms: Cross-sectional study. *JMIR Form Res.* 2021;5(11):e31366. doi:10.2196/31366.

In an effort to assure all abstracts related to presentations given at the ICCEC are published, we would like to include in this issue the following abstract from the Cape Town, South Africa meeting, as it was not available at the time of publication of the 2021 Proceedings.

The Editorial Group

Establishing an Independent Online Clinical Ethics Consultation Service in Response to the COVID-19 Pandemic in Malaysia: The Process and the Organization

Mark Tan Kiak Min, BMedSc, MB BCh BAO, MA, HEC-C

The remit of formal clinical ethics services in Malaysia is still in its infancy stages. The first established clinical ethics service was set up at the Institut Jantung Negara (IJN) in early 2018 and this was followed by the Clinical Ethics Consultation Service (CECS) at the Universiti Teknologi MARA (UiTM) Faculty of Medicine in late 2019. At the beginning of the COVID-19 pandemic, these were the only 2 established clinical ethics services in the country. In anticipation of the escalating COVID-19 situation in Malaysia at the time, and faced with a lack of established clinical ethics support in the country's healthcare system, Clinical Ethics Malaysia (CEM) was formed in April 2020 with the aim of providing clinical ethics support to all Malaysian healthcare professionals who may face ethical dilemmas in their clinical practice during the pandemic. These cases were not necessarily only limited to cases and issues directly involving COVID-19 patients, but also those being an indirect consequence of COVID-19 or those involving non-COVID-19 patients. This is done to support our frontliners because we recognised that the many ethical issues that have arisen and continue to arise as a result of the COVID-19 pandemic may compound an already stressful situation for healthcare professionals leading to an increased amount of moral distress.

Recognising the need and importance of providing timely, context appropriate and ethically sound support to local healthcare professionals, the idea of a virtual clinical ethics consultation service for COVID-19 was mooted. A virtual service would have the benefit of providing healthcare professionals across the country with quick and easy access to ethics experts who were primarily based in the capital. Significantly, by using free platforms such as GoogleDocs, WhatsApp and Zoom, the service could be managed on a limited budget. A referral to this service would be received by a support team who would pass this on to a research team to conduct a literature review and search for relevant resources and articles pertaining to the referral. Together with the case referral, these resources would then be passed to an expert panel for deliberation. As a result of this, a reply containing discussion points and recommendations would be drafted and sent back to the referrer by the support team once it has been finalised. Referrals and replies have also been adapted as templates for teaching clinical ethics.

This presentation aims to share our experience of establishing Clinical Ethics Malaysia and setting up the independent Clinical Ethics Consultation Service. It will cover the reasons for the initial idea of setting up this service and the process of making it a reality. It will also touch on the challenges we faced, and the lessons we have learned in running this service.

JOURNAL OF HOSPITAL ETHICS Volume 8, Number 2

AIMS & SCOPE

The Journal of Hospital Ethics (JoHE) is designed to enhance interdisciplinary discourse in bioethics, and to assist in the development of the practical reasoning and clinical skills required for recognizing, understanding, and managing moral uncertainties and ethical complexities within hospital systems and hospital practice.

EDITORIAL POLICY

The Journal of Hospital Ethics (JoHE) adheres to the editorial standards and authorship criteria recommended by the International Committee of Medical Journal Editors (ICMJE). We welcome submissions of completed manuscripts as well as abstract paper proposals by authors with academic or professional expertise in relevant fields. All contributions to the journal will be reviewed for publication with the understanding that they are not under consideration, accepted, or published elsewhere. Authors of all material accepted for publication will be required to assign copyright to the publisher. Please limit manuscript submissions to 3500 words, and abstract paper proposals to 250 words. JoHE adheres to the American Medical Association Manual of Style (11th Edition).

PEER REVIEW PROCESS

Submissions are subject to an initial, internal peer review by the journal's Editorial Group, an external double-blind peer review, a scholarship/reference review, and a medical/scientific review, prior to full acceptance. Please send all author and submission inquiries to: **JOHE@MedStar.net**

DISCLAIMER

The opinions and perspectives offered in JoHE reflect only the views of the authors and editors, and do not represent the views of others within the MedStar Health system or other institution or organization with which any of the members of the JoHE Editorial Advisory Board are affiliated. Clinical case analyses are entirely fictional. No part of this journal may be reproduced by any process or technique without explicit written permission from the Editorial Group.

For complete information regarding JoHE's publishing policies and best practices, or to subscribe, please visit: **www.medstarwashington.org.** Click on *About MedStar Washington*, *The John J. Lynch, MD Center for Ethics*, then *Journal of Hospital Ethics.*

SUBSCRIPTIONS

The *Journal of Hospital Ethics* is produced and published by the John J. Lynch, MD Center for Ethics. Subscriptions are by volume; each volume consists of 3 issues.

INSTITUTIONAL*……………….…..$100.00

Institutional subscriptions include full network institutional access to all back and current issues via IP validation. Two print copies of each issue are also mailed to your library/institution.

INDIVIDUAL…………………………...$50.00

Individual subscriptions include one print and one e-copy of each issue, mailed directly to the individual subscriber.

INDIVIDUAL BACK ISSUES………....$25.00

Includes an e-copy of a single back issue for non-institutional subscribers.

*INSTITUTIONAL ACCESS

Institutional subscribers are able to access the full run of JoHE volumes directly from their network: Log-in from your home institution and go to www.medstarwashington.org, click on About *MedStar Washington*, *The John J. Lynch, MD Center for Ethics*, then *Journal of Hospital Ethics* to download an e-copy of any issue. Please send all subscription inquiries to: **JOHE@MedStar.net**

The Journal of Hospital Ethics is the official proceedings publication for the International Conference on Clinical Ethics and Consultation (ICCEC) and a partner journal of the American Society for Bioethics and Humanities (ASBH). Members of the ASBH will receive a 30% discount from their subscription to JoHE. All attendees of the ICCEC receive a complementary copy of the conference's proceedings.

INTERNATIONAL CONFERENCE ON CLINICAL ETHICS & CONSULTATION
ICCEC

AMERICAN SOCIETY FOR
BIOETHICS + HUMANITIES

MedStar Health

MedStar Health

John J. Lynch, MD Center for Ethics
MedStar Washington Hospital Center
110 Irving Street, NW
EB 3108
Washington, DC 20010