Volume 7
Number 1
December 2020

JOURNAL OF HOSPITAL ETHICS

THE JOHN J. LYNCH, MD CENTER FOR ETHICS

Features

In Practice

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
Amanda Bush Nursing Ethics, LLC

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

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

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 Hospital Center

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 Hospital Center

Stephen W. Peterson, MD
Physician, Outpatient Behavioral Health, MedStar Washington Hospital Center

Ira Y. Rabin, MD
VP of Medical Operations, MedStar Washington Hospital Center

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

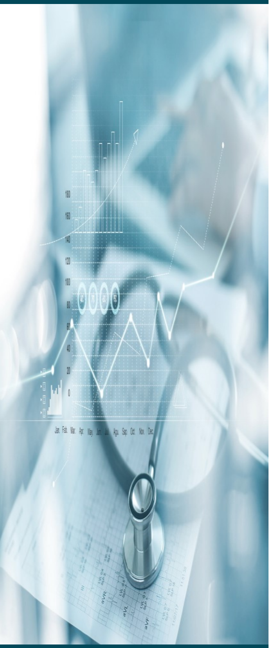
MedStar Health

© Copyright 2020 John J. Lynch, MD Center for Ethics. ISSN (Print) 1938-4955, ISSN (Online) 1938-4920. All Rights Reserved.

Volume 7
Number 1
December 2020

JOURNAL OF HOSPITAL ETHICS

THE JOHN J. LYNCH, MD CENTER FOR ETHICS



JoHE VOLUME 7, NUMBER 1

CONTENTS

Rounding With the Editor

Features

In Practice

ROUNDING WITH THE EDITOR

Does Old-Fashioned Character Matter Anymore?

Evan G. DeRenzo, PhD

Dear Readers,

Welcome to the *Journal of Hospital Ethics* (JoHE), Volume 7, Number 1. All of us at JoHE hope you and yours are healthy and safe. For those of you for whom that is not true, and either you or a family member or friend is sick with COVID-19, or you have experienced the death of a loved one due to this pandemic, please know our hearts are with you. For those who have lost jobs, we hope you can safely return to work, soon. For those of you who are isolated or separated from loved ones who are isolated, we join you in looking forward to the time when we can all be together again.

If managing under conditions of pandemic weren't difficult enough, the death of George Floyd has sparked a renewed time of racial unrest. As I approach my 70th birthday, a white woman who grew up through the social upheaval of the 60's, I have long been alert to my privilege. At times when I have reflected on that privilege, I have often been ashamed. Although my marching days are long over, my spirit still joins all who protest the inequities and brutalities weighing down on our nation. I am embarrassed to see the despotic militarized dispersal of United States citizens peacefully protesting.

For us at the Lynch Center for Ethics, as immense social upheavals swirl around us in the midst of this pandemic, we continue to go into our hospital every day. We continue to round with our Intensive Care Unit (ICU) teams and attempt to provide extra support to those taking care of our patients. We have had, and continue to have, many COVID positive (COVID+) patients. We have lost many but, gratefully, have also sent many more home to their families. We all wear masks. Some wear gloves. We all wash our hands more times a day than I can count. We try to stay socially distanced but it is difficult. We come home, put our clothes in big, green trash bags and jump into hot, sudsy showers. Even that reminds us of those who are wanting, such as those experiencing homelessness while attempting to protect themselves from the coronavirus.

Most hospital visitors are still not allowed unless one of several clinical circumstances, including end-of-life or emergency surgery, is the case. The pandemic has laid bare the inequities in our society. The systematic disassemblage of our democratic institutions during the catastrophe that is COVID-19 has the country reeling. None of us is living in a world we recognize. What a perfect issue of JoHE to be writing about character.

When I started in bioethics, character development was still at the heart of training clinicians. Particularly in the case of physicians, one regularly spoke of the ‘virtuous physician.’ But little by little, focus on character has faded. Looking back on the history of the growth of contemporary bioethics (we need to remember that medical ethics is essentially as old as medicine itself), the formalization of the field contributed mightily to this diminution in attention to character development. Today, when attempting to talk to other bioethicists about teaching and shaping character as a responsibility of a training program, the most charitable response is that attention to character is a quaint anachronism. The less charitable response is distain; because virtue cannot be seen, the response goes, teaching virtue ought to be forgotten. Although virtue accounted for a few pages, at least, of the American Society for Bioethics and the Humanities’ (ASBH’s) first edition of their Core Competencies, alas, all mention of the virtues were wiped clean in the 2nd edition.

Thus, we’re growing new generations of bioethicists who have no thought about what it might mean to lose consideration of virtues such as honor, trustworthiness, honesty and courage, to name a few. How great the loss for our patients and society when our clinicians are not taught how to work on shaping their own characters into being the kinds of persons clinicians ought to be.

Quaintly anachronistic or worse, this has always seemed short sighted to me. It makes a difference to me if my physician went into medicine on the hunt for the fancy car and the big house or if my physician went into medicine out of a genuine impetus to care for sick and vulnerable people. I care if my nurse cares about me rather than being there just to punch a time clock. And COVID is really separating one group from the other. All the clinicians who risk their lives taking care of these patients are owed our deepest gratitude. Those who do their jobs as a commitment of the heart are among the most special people in the world.

Although there are scant data on which to base this hunch,[1] after working with nurses and physicians since I was 14 years old volunteering in my local nursing home, it may be that a solution to some of the most challenging circumstances for caregivers comes as a matter of character development. Working in a busy, urban hospital is difficult enough under the best of circumstances. Under conditions of pandemic while your city and the nation is burning down is beyond one’s wildest imagination. To come into work every day wondering if today is the day one might become infected and die in a matter of weeks is an awful lot to ask of our professionals. Even if a vaccine is developed relatively soon, soon could be another year. And a year can be a very long time.

In the case analyses section of this issue, you’ll see that case 2 is about character. When faced with a moral challenge, how am I going to react? It is an ethics question regarding not justification, but character. Who I am will determine how I will react and how I react will determine how I think and behave. Will I be up to the task? Will I face my obligations with courage or not? Will I begrudge my infectious patients the care they need and that I have signed up to provide? Or will I face my patients with the compassion their plight should elicit from me? Each of us faces with regularity ethical challenges throughout our lives. When faced with ethically improper behavior in others, what does one do? Is it morally acceptable to just shrug one’s shoulders and think, “Not my responsibility?”

If, as is explained in the case, physicians-in-training are judged by the Accreditation Council for Graduate Medical Education (ACGME) on such attributes of character as integrity, if one is supposed to be a person/clinician of integrity (for example, that one is to be truthful with patients), then one must work on being a person who is truthful. If one, for example, is to demonstrate integrity by being courageous, then one has to work on one’s character when called upon to be courageous. And the list of virtues that clinicians are expected to demonstrate is extensive.[2]

If, however, we come to think that teaching the virtues, and teaching how to continually work on one’s own character to better inculcate the practice of the virtues is not the responsibility of clinical ethicists, then who is to help clinicians to learn that being persons of integrity is central? Historically, it was up to senior physicians and senior nurses to teach young clinicians how to think and act and behave. But that, too, has been partially lost.

Although arguably necessary, with the contemporary structure of medicine having gone to shift work, junior physicians and nurses may not have the consistency in mentoring that is required by the task of helping novice clinicians appreciate the need for cultivating skills such as the selfreflectiveness called for to help one refine the contours of one's character. This is, however, certainly the task of clinical ethicists who meet their training mission for their own institutions.

As the consults around death and dying are continually folded into the work of palliative care clinicians, who bill for services that include standard medical activities as prescribing medication, clinical ethicists need to expand their own understanding of what education in clinical ethics entails.[3] And to my mind, at least, it entails education around the house that includes teaching the virtues to medical and nurse clinicians.

Thoughts of this expanded mission for the education activities that should be a cornerstone to any clinical ethics program is exemplified by Clemens Sedmak's article on the dignity and decency surrounding how the environmental services staff of a hospital is treated. We don't want our environmental services staff to be invisible as the article discusses. They are as critical to the excellence of a hospital as anyone else. If they fail to meet high standards, it might not matter how good the neurosurgeons are.

Being respectful of, friendly to, and collegial with a hospital's environmental services staff members calls on the same characterological qualities called for as integrity in the patient/physician relationship. Respectfulness is respectfulness. Being respectful to all hospital teams is a simple matter of character.

Our next article does not turn on matters of character and does, instead, call on the principle of beneficence and theory of utilitarianism to answer a critically important question in hospital medicine; what is the best strategy for management of methicillin-resistant staphylococcus aureus (MRSA) infection? One of the reasons I am so happy that we are publishing this piece is that it is a wonderful example of what is so often missed. This is a perfect instance of what so many might look at as merely a 'technical' issue without appreciating its moral implications. It is the quintessential exemplar of what we, at the Lynch Center, try to communicate with regularity: virtually everything in medicine is a medico-moral issue. That is, provided that one thinks broadly enough to understand that everything performed in a hospital ought to be understood as patient-focused, and therefore carrying moral heft, even interpretation of data to drive a decision such as whether to apply a vertical or horizontal approach to MRSA management has a substantial moral substrate. Zohar Lederman's article just perfectly brings that lesson home.

In our third article we present an excellent and enlightening paper by John Frye, focusing on the real beginnings in our field of developing data collection, analysis and cross-institution sharing and research standards. Although findings indicate standard setting in this area will take some time, that this study was conducted at all should give us all hope for the day when these standards are set.

Many of you will be familiar with a wonderful series of meetings, created by Paul Ford and his colleagues at the Cleveland Clinic, called the UnConferences. They are work meetings where a relatively small group of seasoned clinical ethicists come together to spend a few days working on nagging problems on which the field needs to make progress. One of the most fun and amusing parts of the meetings is when speakers throw questions on the screen and the audience responses are displayed for all. Invariably, when the answers are all over the map its obvious to everyone that whatever the question was about refers to an area in the field that clearly needs work. The data from this initial survey show that we need to be working towards data collection, so we can move on to share all that we learn. But it's clear that we've got a long way to go. Perhaps this is a topic for the next UnConference.

As to our final feature, I couldn't agree more with its conclusions; I suspect you will too. So I'd like to illuminate a particular sliver of the paper, the creative use of their ethics committee members to find family and/or friends of their unrepresented patients. It certainly looks like the paper's authors' hospitals, similar to just about everywhere across the country, have turned their Social Work Departments into Nurse/Social Work Discharge Departments. The disaster that this has caused for patients, families and clinicians is a topic worth much ink and so will have to be set aside. Here, I just want to prepare our reader for the wonderful idea of using ethics committee members with sleuthing skills to come into some cases after social work has given up, to volunteer to continue looking for family or friends of their unrepresented patients. That the paper states that in 90% of the cases they were successful is just icing on the cake.

How perfect, also, that this story brings us back full circle. While thoroughly supporting the importance of such work within a principled framework, I would add that it shines a light on the virtue of perseverance. That these ethics committee volunteers are willing to give of their time and effort to dig deeper than perhaps a stretched social work and/or legal department might have, indeed, results in great rewards.

In the meantime, for those of you who have not been able to escape the miseries of the coronavirus, we hope your burdens weigh less heavily on you and your families in the weeks and months ahead. For those of you who have been able to enjoy time with your family we are joyous for your happiness while coping with a world turned upside down. Let us all look to a day when we, our patients, our families, their families, and our brave and compassionate clinicians can all look back on the time of COVID-19 as a life-altering world event that we have survived and from which we have learned much. And stay tuned for our next issue, devoted entirely to the COVID-19 pandemic.

As always,

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. Leffel GM, Mueller RAO, Ham SA, Karches KE, Curlin FA, Yoon JD. Project on the Good Physician: Further evidence for the validity of a moral intuitionist model of virtuous caring. *Teach Learn Med*. Jul-Sep 2018;30(3):303-316.

2. Kotzee B, Ignatowicz A, Thomas, H. Virtue in medical practice: An exploratory study. *HEC Forum.* 2017; 29(1):1-19.

3. Bain LE. Revisiting the need for virtue in medical practice: a reflection upon the teaching of Edmund Pellegrino. *Philos Ethics Humanit Med*. 2018 Apr 10;13(1):4.

FEATURES

Dignity and Decency: Personal Integrity and Decent Institutions

Clemens Sedmak, PhD

Abstract

The article looks at the culture of human dignity in hospitals through the lens of custodians. By making use of four categories ("job crafting," "moral access," "interior moral anchoring" and "supported integrity") the article develops the concept of decent institutions as institutions that do not humiliate human persons. A culture of human dignity within the context of institutions requires proper attention to "entry points for humiliation" of which there are quite a few in a hospital setting.

Introduction

There is so much that can be learnt from custodians; they see a lot since they have access to the "off-stage" area of an institution. The way an institution treats its custodians says a lot about the moral profile of the institution. Custodians see a lot because they seem to wear (not by choice) the famous ring of Gyges that makes them invisible. Indeed, not infrequently, custodians and cleaners are "invisible" or even "made invisible" (with working hours that do not disturb the day to day business). Cleaners may also experience invisibility through lack of recognition or even acknowledgement of presence; they experience invisibility of work in the sense that their work seems to be ignored or underappreciated.[1] There is also a social imperative for custodians and cleaners to remain invisible, it is perceived as part of a well-functioning institution to take cleanliness for granted: "most of us know when somewhere has not been cleaned but few of us, we suspect, stop to think much about the laboring processes which go into maintaining spaces as clean."[2] The Equality and Human Rights Commission in the UK issued a report about practices in the cleaning sector emphasizing that "workers did not always feel they are afforded the same dignity and respect shown to others in the workplace. A significant number told us they are treated differently and worse than others, harassed and abused. Workers spoke of being 'invisible' and 'the lowest of the low.'"[3]

Custodians can say a lot about the moral status of an institution; their invisibility is the basis for a moral judgment: the experience of "seeing through or past" a person has been identified by Axel Honneth as an indication of a social pathology.[4] There are different ways of not showing respect to a person i.e., acting as if she was not present; acting as if she was an object; acting as if she was not a full person. All these are frustrations of recognition. And recognition is a key category for the ethics of institutions, the ethics of hospitals. The question of "what is not seen" is as morally relevant as the question of "what is not talked about."

Without trying to sound cynical this lack of recognition, this experience of invisibility, offers epistemic possibilities – possibilities to see beyond the surface. The way people inhabit spaces says a lot about these people; the process of cleaning spaces is a very "thick" way of getting to know a space (and the people who spend time in that space). An invisible person has particular possibilities for agency as the above mentioned idea of the ring of Gyges expresses. This is one way to argue for the importance of the custodians' view and experience as an important contribution to epistemic justice.

That is why cleaners and custodians can contribute so much to the discourse on hospital ethics. This may not be the standard narrative; the standard narrative goes more like this: “Cleaning jobs don't usually have any particular educational requirement, not even a high school diploma. A new cleaner typically starts out helping an experienced worker and learns on the job.” The message is that there are not special qualifications or skills involved. Even if it is acknowledged that this may not be the case in a hospital setting with its demanding cleaning challenges[5] the social demands on the custodian are, more often than not, underestimated. Lack of respect for cleaners, representations of cleaning as undemanding, and assumptions that women’s work in cleaning is particularly easy are even to be found in hospital settings.[6] Can there be a counter narrative?

My claim in this contribution is that the decency of an institution (a hospital, in that case) manifests itself in the way it upholds a person’s dignity and allows for persons to act with integrity in the workplace; one specific window into this connection between decency and dignity is the work and work situation of custodians who find themselves at the bottom of the social hierarchy of a hospital (with usually “curing” at the top, “caring” second, and “cleaning” at the low end). Hospitals employ many custodians and cleaners, they are one of the largest employers of cleaning personnel. Custodians can teach us a lot about the moral space in hospitals. Let me analyze two stories that can shed light on the role of custodians.

Jason: “Job Crafting” and “Moral Access”

Kimberly White describes a custodian in a nursing home. His name is Jason: “His primary job was running the floor machine. It was run every day in all the hallways and large rooms, and that’s what he was paid for; that was his entire shift, all day, every day.” [7] Needless to say that this job (in line with the standard narrative) does not require special qualifications or skills. But then White tells the readers something more about Jason: “He does more than he’s strictly paid for. He knows every single last resident of the facility. Every day Jason can be seen to push wheelchairs to and from dining and activities or carrying blankets to an old lady who caught a chill or filling a water jug for an old man who can’t fill it himself. None of these tasks are technically his job, but they are part of the job to him.” [7]

Jason explains his particular way of inhabiting the job by pointing to the residents of the nursing home as his family. This frames his relationship with residents as special obligations towards especially important persons. This is a shift in perspective, a shift that ceases to see persons as objects. The dynamics and temptation to see persons as objects is almost ubiquitous. People frequently see other people as peons in their projects and get frustrated when they do not conform to the expectations.

It goes without saying that there is the possibility of a deconstructing reading of the situation: here is a man who does not have a life outside of work, who has to get through empty weekends, and exploits the relationships his professional context offers for his own emotional benefit; he abuses his role and even steals money from his employer by not sticking to his assigned role and task. Given Kimberly White’s description of the situation and the person, however, this malevolent interpretation is not warranted. It seems plausible to read Jason’s story as the story of a person who saw the residents he worked with as persons and not as “occupational objects.” Occupational objects are entities that are primarily defined by the kind of actions they require; they serve the purpose of structuring the agency of a person and have a function in a person’s radius of action. In the setting of a hospital or a nursing home the temptation to reduce a person to an occupational object is real. A patient’s situation can easily be “read” through the lens of the kinds of treatment that the patient requires. The patient can be reduced to an object of medical treatment and medical procedures.

In order to better understand the dynamics of occupational objects let us ask the question: what is the difference between a person and an artificial and functional object like a pen? Looking at the difference between a pen and a person I would mention four key points: predictability, replaceability, functionality, producibility. An object like a pen is predictable in what it does and in what it can do, in what it can be used for; it is clearly not the point of a pen to surprise its user. A human person, by contrast, can be characterized as a mystery with inexhaustible depth. In fact, it is an important way to approach an understanding of human dignity to see the person as a mystery.[8] A pen is also easily replaceable; if objects are produced in great numbers, they can be replaced by another object of the same kind without any difficulty. You lose a pen, you get a new one; you ruin your pencil you take another one. Functional objects can be replaced, generally without a sense of loss. This is not the case with human persons. The loss of a person is a loss that can never be made up for "as if it never happened." A person cannot be replaced as a person. It is, of course, possible to replace the functional aspect of a person – a job holder can be replaced by another employee to do her job; this works well on the functional level, but not on the level of a person in her uniqueness. It could be argued that the recognition of the uniqueness of a person is an important aspect of honoring the dignity of a person. The Hebrew Bible contains the book of Job; Job is a man who is tested by God and loses his wealth, his children and his health; at the end of the story he regains his health, gets new wealth and other children. But this is clearly not how it works with human persons. The person cannot be replaced *as a person*. Thirdly, a pen is defined by its functionality; there is a clear answer to the question "what is the purpose of a pen?" Pens are produced with a purpose in mind. A pen's value is, at least initially, defined by its usefulness, by the way and extent it can fulfil its function. The human person, in contrast, cannot be reduced to a function or even a set of functions; there is something elusive about the purpose of a person and her life – which inspired Ludwig Wittgenstein to remark in his *Tractatus* (6.521): "those who have found after a long period of doubt that the sense of life became clear to them have then been unable to say what constituted that sense." Fourthly, a pen is an object that can be produced, even mass-produced. We do not use the image or vocabulary of mass production for the human person; the process of educating a person is not a predictable and mechanical process of producing a particular type of being. There is a dimension of "growth" in a person's development that cannot be framed in a language about patterns of production.

Jason was able to see a person as a person with a sense of her uniqueness and her mystery and not as a functional occupational object. In settings like a hospital where the focus is on "treatment and doing" rather than "encounter and being" there is a particular risk of a particular pattern of "seeing-as," a way of seeing persons as occupational objects. Jason resisted this temptation. Reducing persons to objects is one way of humiliating a person, one way of violating a person's dignity.[10] Without trying to sound too naïve, I would like to interpret Jason's work performance as habitually showing respect for persons as persons. Jason, so it seems, cultivated the art of not humiliating the persons he worked with.

In order to draw lessons for an ethic of hospitals from Jason's agency I would like to offer two categories: "job crafting" and "moral access." "Job crafting" is the project of changing and creating relationships, shaping interactions, and (re) defining tasks and aspects of one's job.[10, 11] Job crafting is an important aspect of "inhabiting a role." A professional role is inhabited if it has been appropriated to fit the person of the job holder; the distinction between "inhabited" and "non-inhabited" has been inspired by Aleida Assmann's distinction between "inhabited memory" and "non -inhabited memory".[12] The latter points to museums and archives and memory contents that do not stir emotions, that do not lead to conversations, that do not play a role in people's lives; the former ("inhabited memory") refers to cultures of remembering that shape communication and interactions, that show people's emotions. An inhabited role has been personalized and reflects the style and personality of the role occupant. This is an important aspect of flourishing at the job – French sociologist Alain Ehrenberg has shown that non-inhabited roles can lead to mental health challenges and an "exhausted self," that cannot identify with or shape the role assigned to the individual.[13] Job crafting allows for the uniqueness of a person to come through in a role or job. It can thus be argued that the institutionally granted freedom for job crafting is an important aspect of a decent institution that cultivates a sense of respect for the dignity of the human person. This idea can be substantiated in a dialogue with John Rawls' first principle of justice in his *Theory of Justice* granting a maximum of freedoms to each person.[14]

"Moral access" seems to be a helpful concept as well; it is a category that has been introduced by Eva Feder Kittay in her Presidential Address delivered at the 113th Eastern Division meeting of the American Philosophical Association in Baltimore on January 6, 2017. In her reflections, entitled “The Moral Significance of Being Human,” Kittay works with vignettes that remind us of the humaneness of the person. She mentions the experience of Albert Kurihara, a Japanese-American who was interned after the attack on Pearl Harbor; he comments on his experience: I remember thinking, ‘Am I a human being? Why are we being treated like this?” She also mentions the outcry of Abdel, a twenty-year-old from Afghanistan living in the “Jungle” of Calais, the makeshift camp in France, who says to his interviewer: “They treat us like animals … We are human. They should treat us like humans … These people are someone’s son. They’re someone’s brother.”[15] “Moral access” is the state of having a window towards moral significance. Moral access, in Kittay’s characterization is “access to something that is morally significant in the world. There are times when such significance is entirely transparent to us, when our moral principles guide us in a reliable fashion or when our empathy is already active and we understand how we are to respond. But in situations where another’s plight, struggle, or needs go unnoticed, when we are indifferent or unaware of the impact of our actions on those whom we don’t recognize as moral equals, we need something—a narrative, a tap on the shoulder—to shake us out of our indifference and to gain something that is more than epistemic access to the other. This is access to what the other cares about and her entitlement or right to have these cares taken into account.”[15] Moral access is the important category that combats indifference. Indifference is a major obstacle to moral action. Jason was able to see the persons in the nursing home as “somebody’s child” or “somebody’s sibling.” He had moral access to these situations and provided moral access to others who may be more oblivious of the distinction between a person and the role she inhabits.

“Job crafting” and “moral access” are the two defining categories I suggest to learn from a custodian’s work ethos. A decent institution, i.e. an institution that is committed to respecting the dignity of human persons, will create spaces for “job crafting” and promote a culture of “moral access” to each situation and each person, irrespective of role or function. “Job crafting” and “moral access” are important aspects of upholding the difference between a person and an occupational object.

Luke: “Interior Moral Anchoring” and “Supported Integrity”

Let us now turn to a second story. Barry Schwartz describes a particular scene with Luke, a custodian in a major teaching hospital.[16] Luke had to clean the room of a young patient who had fallen into a coma after a fight; the comatose patient’s father had been keeping vigil for months at his son’s bedside. One day the father left his place next to his son’s bed and went out to smoke a cigarette; during these minutes Luke cleaned the room. Later, Luke encountered the patient’s father in the hall and the father was furious, yelling that the room had not been cleaned. Luke apologized and cleaned the room a second time, before the eyes of the father.

This situation can be read from many different perspectives – it can be read critically pointing to the power gap between the patient’s father and the custodian (whose place in the hospital hierarchy is normally quite low) or to the failed learning opportunity of a person (the patient’s father) who made unwarranted judgments and accusations and could not control his anger. One could entertain the assumption that Luke had acted out of fear given the constraints of a hierarchically structured institution within a context of frequent litigations and a culture of chronic “tribunalization” where human agency and human interactions are primarily seen through a legal lens. In this setting the distinction between “legal” and “illegal” and the category of “compliance” can easily become the most prominent structuring elements of the space of action and interaction. Standardized processes and a corresponding culture of accountability are manifestations of this legalization of institutional cultures.

This reading of the situation seems plausible but the interview with Luke provides some background that would justify a different reading. Luke is quoted with the sentences, “at first, I got on the defensive, and I was going to argue with him …

Something caught me … I cleaned it [the room] so that he could see me clean it … I can understand how he could be. It was like six months that his son was here. He'd be a little frustrated, and so I cleaned it again. But I wasn't angry with him. I guess I could understand."[16] Luke's testimony points to significant similarities with Jason's way of doing his job; there is a sense of seeing a person as a person and the institutional space to do so (one could envision scenarios where Luke would not have the time or permission to spend working hours on an already cleaned room). Luke's situation shows yet again "job crafting" and "moral access."

Based on an interpretation of the situation that stresses Luke's agency (rather than institutional patterns of suppression) I would like to offer the following observations: deep perception, discomfort ability, hesitation-based respect.

We see "deep perception" at work; it is remarkable that Luke saw the father of the comatose patient as a deeply concerned and frustrated man. He saw the father as a human person who cared about his son, as a social agent with commitments, as a vulnerable being challenged by a frustrating experience with unclear prospects. The ability (and willingness) to engage in deep perception that reaches beyond the surface level and the perception of roles and functions are an aspect of "dignity-literacy." The insight that a person is so much more than the role she inhabits is an important way of honoring the dignity of the human person in her uniqueness and inexhaustible richness. Dignity therapy works with this very idea that a person should not be reduced to the present state or role she finds herself in; seeing the richness and depth of a person is an intentional effort to respect the person's dignity.[17] In this sense a human person is a mystery that "never finishes saying what it has to say," to use Italo Calvino's famous characterization of "a classic." As in Jason's case above, we encounter a sense of the mystery of the person. A person is so much more than the role she inhabits – be it the role of a patient, the role of a patient's family members, the role of a custodian. Luke could see beyond the obvious and the observable. Secondly, Luke displayed what I would call "discomfort ability," the ability to deal with discomfort and inconvenience without high levels of personal frustration. If the default position is "comfort" then the road to "comfort" is: "convenience." It is clearly inconvenient to be unjustly accused of malpractice; it makes a person feel uncomfortable and without the ability to suffer discomfort for a higher good the response to such accusations would be defensive behavior. It takes a lot to put another person's moral wellbeing above one's own. It takes the ability to accept injustice for a higher cause. In cultures that emphasize reputation and image one would be justified to use the term "sacrifice" for what Luke decided to do. Thirdly, Luke's agency could be approached with the category of "hesitation-based respect." In the above mentioned quotation we can hear him say: "at first, I got on the defensive, and I was going to argue with him … Something caught me …" – this is an interesting detail. It is as if Luke was waiting on a threshold before entering the room of anger, metaphorically speaking. Simone Weil has described the attitude of "waiting" and "hesitation" as an important aspect of respectful living.[18] There is a moment on the threshold when encountering the other. Luke hesitated before he engaged in possibly heated exchange with the father; he paused for a moment – or something (his perception, his value landscape?) made him pause. Because of this pause he was able to show respect for the father's difficult situation.

Deep perception, discomfort ability, and hesitation-based respect can be used as categories to make sense of and frame Luke's agency. Again, it is remarkable that the institutional setting allowed for these behavioral features. In his interpretation of Luke's acting Barry Schwartz used the category of "practical wisdom" (which can also be translated as "prudence") as his main lens of interpretation.[16] It is remarkable that the institution supported prudential judgment and agency in this situation. There are lessons to be learned for an ethic of institutions beyond this particular situation - let me make use of two further categories: "interior moral anchoring" and "supported integrity."

"Interior moral anchoring" points to the dynamics that Luke could drink from moral wells that were not part of the situation – he could motivate his behavior from sources that were not recognition-providing sources in the given situation. In other words, he could anchor his moral performance from within, from inner beliefs beyond the external motivation the situation itself could provide. In a paper on moral psychology Naomi Ellemers and her co-authors have used the term "social anchoring" (of right and wrong) to refer to the set of social expectations and cultural codes that shape moral behavior and moral attitudes.[19] The term "anchoring" points to the basis and foundation, to the roots of a moral performance. Luke was rooted in values beyond the dynamics of the situation. That is why he showed a remarkable "freedom from situational recognition needs." This is to say that Luke did not use the situation to gain reputational capital. It takes a lot to allow for an unjustified damage of one's image and reputation. Erving Goffman famously described the human person as being constantly engaged in image work (building up, preserving, defending, rehabilitating).[20] Luke was able to draw on sources beyond the situation and did not have to squeeze recognition for himself out of the encounter with the patient's father. This is possible if there are higher values and stronger commitments than the value of situational recognition and the commitment to high reputation. Luke showed rootedness beyond and above the particular situation, i.e. interior moral anchoring.

The second category I want to use to interpret Luke's behavior and agency is the category of "supported integrity." "Integrity" is a key category of moral philosophy.[21, 22, 23] It basically refers to four aspects: sincerity and honesty; seriousness and earnestness; robust concern and holding a position; integrating the different aspects of the person and life. A person of integrity, in this reading, is honest and not deceptive, faces reality and does not fall into the trap of self deception; she accepts that it makes a difference how we live our lives and which kinds of decisions we make and acknowledges that a lot is at stake when we ask the question what really matters; she has a sense of what she cares about and is motivated by robust concern based on positions she holds and is willing to defend and pay a price for; finally, she is able to integrate the different facets of life into some kind of consistent "whole" that does not allow for a compartmentalization of life. I would qualify Luke's integrity as "resilient integrity" because he was clearly faced with morally adverse circumstances (the unjust and highly emotional accusation of neglecting his duties) and showed a commitment to a moral compass prepared to see a person in her depth. This resilience was supported by the institutional setting, so it seems. Luke was able and had the freedom to clean the room a second time. He could comply with his moral standards, could live up to his self-determined idea of integrity.

Decent Institutions

The two stories with the four categories of "job crafting," "moral access," "interior moral anchoring" and "supported integrity" point to persons as much as institutions. Decent institutions are dignity-literate institutions. They allow employees to craft their roles in a way that allows them to work with integrity and have moral access to the people they work with. Decent institutions encourage the space to act in consonance with one's justifiable moral beliefs. It is one of the major challenges of a toxic work environment not to be able to work in accordance with one's own moral and professional standards. In short, decent institutions treat persons as if they were persons (rather than occupational objects). Treating persons as persons requires the moral space to, at least in principle, see a person in her uniqueness and craft interactions accordingly.

The infamous Mid Staffordshire hospital scandal in the United Kingdom that has led to an estimated number of 400-1200 excess deaths between 2005 and 2009 has shown the risk of reductionism, of reducing patients to occupational objects that serve the goal of reaching targets. It has been established that the definition of financial and clinical targets has led to a dynamics "that these targets were pursued with a reckless disregard for the well-being and safety of patients." [24] The toxic dynamics in the hospital were created through efficiency-driven pressure leading to negative reactions to this pressure (like fear and disengagement) resulting in poor behavior which then became habitual.[25] The scandal reflects a thinking where efficiency has emerged as the highest value. We may recall Adorno's famous observations in his *Education after Auschwitz* about the manipulative character who is defined by efficiency: "The manipulative character—as anyone can confirm in the sources available about those Nazi leaders—is distinguished by a rage for organization, by the inability to have any immediate human experiences at all, by a certain lack of emotion, by an overvalued realism. At any cost he wants to conduct supposed, even if delusional, *Realpolitik*. He does not for one second think or wish that the world were any different than it is, he is obsessed by the desire of doing things …, indifferent to the content of such action. He makes a cult of action, activity, of so-called *efficiency* as such which reappears in the advertising image of the active person." [26] The claim is that institutions and persons who value efficiency the most will lose their humanity.

It is again custodians who can say a lot about the implications of an ethos of efficiency. Natalie Walters who worked for a year as a janitor summarizes important lessons she has learnt: "People are generally self-absorbed." This means in concrete terms from a custodian's perspective: "Many people don't think about how their actions – even seemingly insignificant ones — affect others. For instance, when people go to the bathroom, they aren't thinking about aiming right so someone else doesn't have to clean up their mess, or about picking up the paper towel when their free-throw misses the trash can. No. They are thinking about finishing their business as quickly as possible so they can get out and get on with their life." [27]

Decent hospitals will value efficiency – but not as the highest value; decent hospitals will value proper management, but not based on the idea of "maximizing profits." A particularly awful aspect of working in the Mid Staffordshire Hospital was the fact that employees were forced to betray moral and professional standards; they were denied the appropriate moral space. "A working environment can become so stressful or understaffed and under-resourced that staff feel compelled to accept poor standards and over time will become inured to the consequences for patients." [28] Employees at the hospital were forced in situations (or found themselves in situations) where they humiliated persons. "At the ward level this effectively meant many patients went unwashed unattended, to the extent of sometimes being covered in faeces, and in many cases went without proper fluids, nutrition or medication." [24] A patient's daughter reported seeing her mother "in bed with the cot sides up and she hadn't got a stitch of clothing on. I mean, she would have been horrified. She was completely naked and if I said covered in faeces, she was." [28]

Entry points for humiliations is a major criterion for the decency of an institution – the concept of "humiliation" has been identified as a key aspect of an ethic of institutions: "Humiliation is any sort of behavior or condition that constitutes a sound reason for a person to consider his or her self-respect injured;" [9] Margalit has identified three major ways of humiliating a person: treating persons as if they were not human; performing actions that lead to a loss of basic control, especially control over bodily functions; excluding a person from the human family.[9] A hospital is a context that is particularly sensitive to entry points for humiliation – persons can be reduced to occupational objects; they may find themselves in delicate situations with fragile body conditions and limited control over the body. There are issues with bodily shame, nakedness, standardized clothing,[29] and a loss of control over basic bodily functions; there are issues with privacy and personal control over the environment and interactions; there are challenges with the objectification of persons by reducing a person not only to the role of a patient, but even to the body part(s) under treatment. Patients are at high risk of being humiliated and experiencing shame because of the perception of diseases as defects and the necessary exposure in a medical context.[30] Decent hospitals do not humiliate persons; they will be particularly sensitive to entry points for humiliation. A systematic mapping of entry points for humiliation seems highly recommendable. This is again a field where custodians could work as seismographs of the culture of respect within a hospital. This culture is undermined through disruptive behavior, humiliating practices, dismissive treatment of patients; a major contributor to disrespectful behavior in a hospital setting is "production pressure" which again points to a culture of non-moderated efficiency.[31]

One important way of monitoring efficiency and of bringing about an appropriate professional culture in a hospital is a "culture of accountability." It is undeniably important to have standards and standardization, procedures and processes, a culture of documentation, mechanisms of monitoring and evaluating. However, there is a tipping point when "accountability" becomes self-referential and self-serving. Part of the scandal in the Mid Staffordshire hospital was the fact that "the board of the hospital trust seemed more preoccupied with looking upwards to regulators and performance management bodies … rather than looking inwards to its staff, patients and clinical services, or outwards to the population of Stafford."[25] Let me introduce the term "self-referential actions;" these are actions that do not make sense for the relevant players while performing the actions; the value of these actions does not lie in "what they do," but "that they have happened." They are legitimized by the fact that they have been performed. Let me provide an example from a non-hospital setting: I once took a group of students to a foreign country and was asked by the University to go through a risk management session; we talked about earthquakes and volcano eruptions, terrorist attacks and political coups; I questioned the usefulness of these elements of the training and was told: 'this will probably not be useful to you when something like this happens, but it is important for us to be able to say that we did that training if something happens.' This is an example of a self-referential action owed to a culture of accountability. The value of the action is "being able to say we did it." We could think of similar examples in hospital settings, e.g. procedures around informed consent. Onora O'Neill has observed almost two decades ago that a culture of accountability cannot replace or cultivate trust.[32] She argued that – notwithstanding the importance of standardized procedures – there has to be space for judgment, and a culture to value the judgment of persons. In other words, there has to be the moral space to craft one's agency in a uniqueness that may occasionally go beyond or against the standardized procedure. And, we can add, this judgment needs to balance rational and emotional elements. Emotional awareness is necessary for moral perception which is the basis for moral performance.[33] It ensures that the person in a work setting can see herself and comport herself as a person.

Concluding Remark

Custodians see a lot, can share a lot and can contribute to well-balanced judgments about institutions as the example of Tim Will Hunter with his *Custodian Chronicles* where he paints a picture of the American Public School System has shown.[34] The same exercise could be made in a hospital context. Decent hospitals do not humiliate persons; custodians are important witnesses for the culture of respect in a hospital. Decent hospitals provide the moral space for its stake holders to craft their roles in a way that they can act with integrity having gained moral access to the people around them.

AUTHOR

Clemens Sedmak, PhD is Professor of Social Ethics at the Keough School of Global Affairs and Concurrent Professor of Theology at the University of Notre Dame. He is also the Co-Director of the Center for Ethics and Poverty Research at the University of Salzburg, Austria. His most recent books include: *The Capacity to be displaced. Resilience and inner strength* and *Absolute poverty in Europe. Interdisciplinary perspectives on a hidden phenomenon* (co-edited with H. Gaisbauer, G. Schweiger).

REFERENCES

1. Rabelo V.C., Mahalingam R. "They really don't want to see us": How cleaners experience invisible 'dirty' work. *Journal of Vocational Behavior.* 113 (2019): 103-114

2. Herod A., Aguiar L. Cleaners and the Dirty Work of Neoliberalism. *Antipode* 38,3 (2006) 425-434

3. Equality and Human Rights Commission. The Invisible Workforce: Employment Practices in the Cleaning Sector. Findings Report. London 2014 https://www.equalityhumanrights.com/en/publication-download/invisible-workforce-employment-practices-cleaning-sector

4. Honneth A. Invisibility: On the Epistemology of 'Recognition'. *Proceedings of the Aristotelian Society*, Supplementary Volume 75,1 (2001) 111-126.

5. Eigenstetter M., Galushko L., Jäger E., Olesch S., Blaszk, A. Reinigung im Krankenhaus an der Schnittstelle zwischen Arbeitssicherheit und Hygiene. *ASU Zeitschrift für medizinische Prävention* 53 (2018) 256–263

6. Messing K. Hospital Trash. Cleaners Speak of Their Role in Disease Prevention. *Medical Anthropology Quarterly* 12,2 (1998) 168-87

7. White K. *The Shift. How Seeing People as People Changes Everything*. Oakland, CA: Berrett-Koehler 2018

8. Hanvey J. Dignity, Person and Imago Trinitatis. In: C. McCrudden, ed. *Understanding Human Dignity.* Oxford: OUP 2014, 209-229

9. Margalit A. *The decent society.* Cambridge, MA: Harvard University Press 1996

10. Wrzesniewski A., Dutton J.E. Crafting a Job: Revisioning Employees as Active Crafters of Their Work. *Academy of Management* Review 26,2 (2001) 179-201

11. Wrzesniewski A., LoBuglio N., Dutton J.E., Berg J.M. Job Crafting and Cultivating Positive Meaning and Identity in Work. *Advances in Positive Organizational Psychology Volume 1* (2013) 281–302

12. Assmann, A. *Cultural Memory and Western Civilization: Functions, Media, Archives*. New York, NY: Cambridge University press, 2011

13. Ehrenberg A. *The Weariness of the Self: Diagnosing the History of Depression in the Contemporary Age*. Montreal: McGill-Queen's University Press 2010

14. Rawls J. *A Theory of Justice.* Cambridge, MA: Harvard UP 1971

15. Kittay E.F. The Moral Significance of Being Human. *Proceedings and Addresses of the American Philosophical Association* 91 (2017) 22-42

16. Schwartz B. Practical wisdom and organizations. *Research in Organizational Behavior* 31 (2011) 3-23

17. Chochinov M.H., Hack T., Hassard T., Kristjanson L.J., McClement S., Harlos M. Dignity Therapy: A Novel Psychotherapeutic Intervention for Patients Near the End of Life. *Journal of Clinical Oncology* 23, no. 24 (August 20, 2005) 5520-5525

18. Maier C.T. Attentive Waiting in an Uprooted Age: Simone Weil's Response in an Age of Precarity. *Review of Communication* 13,3 (2013) 225-242

19. Ellemers N., v.d. Toorn, J., Paunov, Y. The Psychology of Morality: A Review and Analysis of Empirical Studies Published From 1940 Through 2017. *Personality and Social Psychology Review* 2019, Vol. 23(4) 332–366

20. Goffman E. *The Presentation of Self in Everyday Life.* New York: Doubleday 1959

21. Calhoun C. Standing for Something. *Journal of Philosophy* XCII (1995) 235–260

22. Halfon M. *Integrity: A Philosophical Inquiry.* Philadelphia: Temple University Press 1989

23. Korsgaard C. *Self-Constitution: agency, identity, and integrity.* Oxford: Oxford University Press 2009

24. Roberts D.J. The Francis report on the Mid-Staffordshire NHS Foundation Trust: putting patients first. *Transfusion Medicine* 23 (2013) 73–77

25. Smith J., Chambers N. Mid Staffordshire: a Case Study of Failed Governance and Leadership? *The Political Quarterly* 90,2 (2019) 194-201

26. Adorno T. Can One Live After Auschwitz? In: *A Philosophical Reader.* R. Tiedemann, ed. Stanford, CA: Stanford UP

27. Walters, N. 9 life lessons I learned from being a janitor for a year: https://www.businessinsider.com/lessons-i-learned-as-a-janitor-2015-9#1-people-are-generally-self-absorbed-1

28. Francis R. Mid Staffordshire – some reflections for clinicians. *Trends in Urology & Men's Health*. November/ December 2013, 17-20.

29. Bergboom I., Pettersson M., Mattsson E. Patient Clothing – Practical Solution or Means of Imposing Anonymity? *Journal of Hospital & Medical* Management 3,3.22 (2017) 1-6

30. Lazare A. Shame and Humiliation in the Medical Encounter. *Arch Intern Med* 147 (1987) 1653-1658

31. Leape L., Shore M.F., Dienstag J.L., Mayer R.J., Edgman-Levitan S., Meyer G.S., Healy G.B. A Culture of Respect, Part 1: The Nature and Causes of Disrespectful Behavior by Physicians. *Academic Medicine* 87,7 (2012) 1-8

32. O'Neill O. *A Question of Trust.* Cambridge: CUP 2002

33. Malterud K., Hollnagel H. Avoiding humiliations in the clinical encounter. *Scandinavian Journal of Primary Health Care* 25 (2007) 69-74

34. Hunter TW. *The Custodian Chronicles, vol. 1*. Create Space Independent Publishing Platform, 2017.

The Ethics of MRSA Management in Healthcare Settings

Zohar Lederman, MD, PhD

Abstract

In this paper I argue for the implementation of horizontal strategies in the prevention of Methicillin-Resistant Staphylococcus Aureus (MRSA). I first review and explain what horizontal and vertical strategies mean in this respect. I next review the empirical evidence supporting each strategy, suggesting that horizontal strategies seem empirically superior. I then discuss the potential harms associated with vertical strategies, namely quarantine and isolation. Consequently, I make a normative argument supporting horizontal strategies.

Introduction

Methicillin-Resistant Staphylococcus Aureus (MRSA) is a ubiquitous heterogenous group of bacteria, capable of causing various kinds of infections in humans, including endocarditis, cellulitis[1], and pneumonia. The bacteria normally reside in human nostrils and other tissues and can cause infection upon entry through the skin. Initially MRSA was restricted to hospital settings, but it is now as common- or even more common, particularly in children- in both the community and hospitals as *Methicillin-Sensitive Staph. Aureus*, at least in some geographic locations.[2–7]

Due to concerns of nosocomial (hospital-associated; the more accurate term now is 'Healthcare-associated') transmission hospitals worldwide and regulatory and professional organizations set regulations and protocols for the screening and management of patients who potentially carry the bacterium, be they symptomatic or asymptomatic. In essence, strategies involve sampling bodily tissues, performing laboratory tests such as polymerase chain reaction (PCR), and then initiate contact precautions.[7] These precautions include isolation of the patient and donning of gloves and gowns before entry into the patient room and/or before patient physical contact. These precautions, while being extremely common,[8] are based on several studies conducted some four decades ago which had significant methodological weaknesses[3,5,9] (for example see the study by Papia[10]). As one editorial comments:

"…the vast majority of the studies were single-center, observational, nonrandomized, before-and-after evaluations, which yielded low-quality evidence and precluded the establishment of causality." [11]

Many public health policies, such as fever screening at airports[12] or culling of wild animals during infectious disease outbreaks[13] are based on low or no evidence. They may be ethically justified when there is simply no better evidence available, and/or where the harm caused by these policies is minimal. However, they become less and less ethically justified as more and more evidence is produced that counters these policies or justifies other policies. The low-level evidence policies also become less ethically justified in opposite correlation with the harm they engender-the more harm they cause, the less justified these policies become.

Vertical strategies for MRSA management are geared towards patients who carry MRSA and who may be symptomatic or asymptomatic. It emphasizes screening of patients through the use of nasal swabs for example. Horizontal strategies for

MRSA management on the other hand are geared towards all patients regardless of MRSA carrier status. They put less emphasis on screening but rather emphasize decolonization of patients regardless of carrier status.

In this paper I argue that vertical management strategies for MRSA management in the hospital settings- including designated screening and contact precaution- are ethically unjustified for two reasons. First, they are less effective than horizontal strategies. Second, they are costly and may cause harm to patients, families and visitors, as well as healthcare providers.

In making my case, I first provide a brief explanation of vertical and horizontal strategies. I then review the most current evidence regarding MRSA management strategies, concluding that horizontal strategies seem to be more effective than vertical strategies. I proceed to review the potential harms caused by contact precautions, entailed by vertical strategies. I conclude by articulating the main argument, that specific screening for MRSA and contact precautions with patients who are asymptomatic or symptomatic carriers is ethically unjustified. I introduce several caveats to this argument, for instance the ubiquity of MRSA in the community as compared to other resistant bacteria. For ease of reading, I first provide a short list of definitions:

Asymptomatic carrier: A patient with confirmed MRSA in one or more tissues who lacks symptoms and signs that correlate with the symptoms and signs commonly caused by the pathogen.

Community acquired MRSA infection: any such infection diagnosed in the outpatient setting or within 48 hours of hospitalization barring the following factors: hemodialysis, surgery, hospitalization during the previous year or residence in a long-term care facility, presence of indwelling catheter or percutaneous device, and previous MRSA isolation.[4]

Screening: Performance of a test to identify the presence of MRSA in one or more tissues.

Symptomatic carrier: A patient with confirmed MRSA in one or more tissues who presents with symptoms and signs that correlate with the symptoms and signs commonly caused by the pathogen (this definition differs from the common definition of ‘carrier’ which usually only refers to persons with confirmed infection but no manifestations).

Standard precautions: Prevention practices that apply to all patients regardless of risk or infection status. These include hand hygiene and protective equipment.[14]

Management of MRSA in the Hospital: Strategy

Patients may acquire MRSA either from the community or during their stay at healthcare institutions. Healthcare-associated infections, particularly by resistant bacteria, are extremely costly and harmful worldwide.[3,4,15–17] MRSA is the most common hospital-acquired pathogen, accounting for example for one-fifth of all hospital-acquired infections in the UK.[15] Regardless of the source of transmission, MRSA is currently extremely common. A 1999 study identified MRSA in 3.4 per 1000 admissions in a large hospital in Ontario, Canada.[10] One large study published in 2004 found that 3.4% of all patients admitted to various wards in hospitals in the USA had MRSA in their nares. It also found that 3% of patients in the different wards became carriers during their hospitalization.[2] A 2011 study of roughly 2500 patients admitted to medical and surgical ICUs in the USA found MRSA prevalence to be 38%-46%.[9] A more recent UK study found prevalence of MRSA upon admission to various wards to be 1.7%; 0.47% out of 10,017 patients acquired MRSA during hospitalization.[18] In 2003, MRSA accounted for 59.5% of all *Staph. Aureus* infections in ICUs belonging to the National Nosocomial Infection Surveillance (NNIS) system in the USA.[3, p. S167] In the early 2010s, MRSA accounted for 28%- >70% of all Staph. Aureus isolates in hospitals in Asia.[4]

Vertical management strategies are geared towards those who were found to carry MRSA. They first emphasize screening to detect MRSA carrier status and then employ measures to treat or decolonize patients. They usually include isolation of symptomatic or asymptomatic carriers in a single room or a cohort, meaning confined to a specific geographic location.[10,14,15] Strategies also include contact precautions, as recommended by the Society for Healthcare Epidemiology of America, the Infectious Disease Society of America, and the Centers for Disease Control and Prevention.[8,9,14]

In one public, academic-affiliated hospital in Israel, for instance (author's own former practice), screening for MRSA is conducted in the following cases:

1. **Prior to surgery**
2. **High-risk patients upon admission, including those with confirmed MRSA carriage who have not been screened in the past month.**
3. **Medical tourism**
4. **All patients upon admission to the intensive care unit (ICU), including pediatric, cardiac and adult ICUs.**
5. **New patients to the dialysis unit who have been admitted in any hospital in the last six months.**
6. **Once-weekly in the respiratory, neonatal and pediatric ICUs.**

Swabs are taken from the nares. Asymptomatic carriers (including those with a recent history of MRSA carriage) and symptomatic carriers are then placed in an isolated room or grouped in the same geographic location. Medical equipment such as a stethoscope is made available for the staff to be used in the particular patient or patients in isolation. The staff members must then inform the infection-prevention unit or the principal nurse on shift. Cessation of a carrier status is possible only by the infection-prevention unit.

Transport of the patient to any other area in the hospital, for an exam for instance, is to be coordinated such that contact with other patients is minimized. At the end of the transport, any equipment that was used should be sanitized. Patients who await surgery are preferably scheduled at the end of the day. In other cases, a window of half an hour before the next surgery must be provided to assure adequate sanitization of the operating theater.

Importantly, visitors are only advised to be scrupulous about hand hygiene upon entry into and exit from the patient's room. Only those visitors who take active part in the patient's care are advised to don gowns and gloves. MRSA carriage should be documented in the patient's discharge letter and the patient is advised to notify other medical institutions about his MRSA status.

Centers for Disease Control and Prevention (CDC) formerly recommended that isolation may be discontinued if three nasal swabs, taken at least one week apart, are negative for MRSA.[19] This recommendation however has been criticized as being based mostly on expert opinion rather than rigorous evidence,[19,20] and does not appear in the newer CDC recommendations.[3,14]

Horizontal strategies employ little or no screening. They rather employ measures across all patients regardless of MRSA carrier status, such as the universal use of the antibiotic mupirocin intranasally.

Management of MRSA in the Hospital: Evidence

In reviewing vertical management strategies, since these management strategies emphasize screening, the evidence for screening is also relevant. Many studies have explored the effects of increased screening and thus increased rates of contact precautions on MRSA transmission, largely failing to report statistically significant positive consequences compared to standard sterilization strategies.[8,9,20] A 2017 study in a large hospital in London for example demonstrated that early diagnosis of MRSA upon admission failed to lower MRSA transmission rates during hospitalization.[18] Another study in a large hospital in Ottawa, Canada compared screening of all patients upon admission (which would then lead to isolation precautions) and selective screening of high-risk patients and found that the latter was more efficient and cost-effective.[21] A large 2011 study conducted in 19 intensive care units (ICUs) in the USA examined the effects of early screening and identification of MRSA infection on healthcare providers' hygienic behavior and incidence of MRSA infection. It found no statistically significant differences.[9] Another study, published in 2005, explored the effects of isolation of asymptomatic and symptomatic carriers either in private rooms or cohort isolation. This prospective study took place in three general medical and surgical ICUs in two hospitals in London.[15,16] In brief, the study compared MRSA transmission rates in periods in which patients were isolated compared to periods in which patients were not isolated. Transmission rates were found to be identical in both periods.

In terms of horizontal strategies, the strongest evidence to date demonstrating the superiority of these strategies over vertical strategies is provided by the REDUCE MRSA study published in

2013.[16] It included 43 hospitals and more than 74,000 patients in the USA. In this cluster-randomized study adult ICUs were randomized to one of three groups. Group 1 included bilateral sampling of nares upon admission and contact precautions in case of positive results or known carriers. Group 2 included similar screening and contact precautions but also a targeted decolonization consisting of intranasal mupirocin twice daily and daily bathing with chlorhexidine-impregnated cloths for 5 days. Group 3 included universal decolonization, whereby all patients were decolonized with intranasal mupirocin twice daily for 5 days and chlorhexidine-impregnated cloths during their entire stay. Contact precautions were similar to the other groups, and no screening was conducted. Primary outcome was ICU-attributable cultures positive for MRSA. Secondary outcome was ICU-attributable MRSA bloodstream infections and ICU-attributable bloodstream infections due to other pathogens. The study found that group 3 performed significantly better in regard to the primary outcome with 37% reduction in ICU-attributable MRSA bloodstream infections and 44% reduction of bloodstream infections due to pathogens other than MRSA.

Adverse Effects of Contact Isolation

MRSA contact precautions- as part of vertical management strategies- carry several potential or actual negative consequences (presented here in arbitrary rather than lexical order). First, contact precautions are more expensive. Second, contact precautions harm patients. They do so by increasing rates of depression and anxiety, increasing delays and non-infectious adverse effects, and decreasing provider-patient contact. In fact, this second consequence is reflected in documented decreased patient satisfaction due to isolation precautions. Third, contact precautions potentially harm relatives and visitors (henceforth, ‘visitors’), again because of decreased contact with patients. Fourth, contact precautions potentially harm and delay the work of healthcare providers, who must don gowns and gloves before entry into the patient’s room or patient contact. These are elaborated below.

Extra Costs. Calculating the added costs of contact precautions is obviously burdensome as costs are highly country- and hospital- specific, often including ‘hidden costs’ that are difficult to quantify.[19] One recent study conducted in surgical and internal medicine wards in a large hospital in Basel, Switzerland found that contact precautions cost an extra $160 per patient per day. The extra costs covered isolation equipment such as extra gloves and gowns, additional cleaning materials, extra workload, and miscellaneous expenses such as curtain changes.[17] Another UK-based study estimated costs of contact precautions in the ICU to be £306.93 per patient per day. [22] While costs may vary according to hospital wards, e.g. ICU, internal departments, emergency departments etc. and countries, the point is that contact precautions do entail extra costs, at a time where national healthcare systems are financially stressed as it is.

Harm to Patients. Contact precautions may engender several kinds of actual or potential harm to asymptomatic or symptomatic MRSA carriers.[19] Two reviews[8,23] have documented the following harms to patients with any resistant bacterial infection and in different wards. First, contact precautions decreased patient-healthcare provider contact in different wards, defined as room entry and duration of stay in the room. This may potentially harm patient care by negatively affecting the quality of history taking and physical examination, as well as by decreasing attention to patients’ needs. For example, a study specifically focused on carriers of MRSA found that isolated patients were less likely to have their vitals and progress notes documented.[24] Second, patients on contact precautions took longer to be admitted to the internal medicine department from the ED compared with other patients. Contact precautions also caused a delay in the transfer of patients to other institutions, potentially preventing patients from receiving adequate care in an institution that is more fitting to their needs. This may at least partially explain the additional finding that patients on contact precautions experienced more preventable adverse effects, such as falls, pressure ulcers and electrolyte disorders compared to patients not on contact precautions.[24] Patients on contact precautions also had worse medical documentation and testing, such as lower rates of stress testing for patients with heart failure. Third, patients (mostly in rehabilitation wards and elderly)[25] on contact precautions had higher rates of depression[26] and anxiety, and increased feeling of loss of self-esteem and loss of a perception of self-control compared with patients not on contact precautions. This increased harm to patients may be reflected in the finding that patients on contact precautions expressed more anger, complained more, either formally or informally, and were overall less likely to recommend the hospital to others.[23,24]

Harm to Visitors. Data regarding harm to visitors seem to be extremely limited, so my notes here are necessarily anecdotal and mainly speculative. From my own experience, visitors do not adhere to isolation precautions, despite instructions by staff. This non-compliance stems at least partially from the inconvenience associated with repeatedly donning and removing the protective gear. This was indeed confirmed by a small survey of 31 visitors in a hospital in Madison, Wisconsin, USA. Importantly, the inclusion criteria were adult visitors of patients with *Clostridium Difficile* infection, but since the isolation requirements are identical, the finding may be applied in our case as well. Only 42% of visitors reported full compliance with isolation precautions, reportedly mainly lamenting the heat and discomfort due to the gown and gloves.[27]

Harm to Healthcare Providers. Intuitively, and anecdotally, one might hypothesize that isolation precautions harm healthcare providers (HCPs) by adding extra burden to their already- overburdened daily schedule: donning gowns and gloves may indeed require a mere minute or two, but doing so several times daily for several patients in the midst of a stressful work schedules, primarily for junior physicians and nursing staff may be harmful in terms of time constraints and predisposition for burn-out. Furthermore, isolation precautions potentially mean an increased risk of MRSA transmission for HCPs, their families and even their pets,[28] and awareness of that risk may itself harm HCPs. Of course, such awareness may motivate HCP to take precautions against infection, and thus reduce transmission risk to their families and pets, but this possibility needs to be tested empirically. In any case, I could not find any objective studies assessing the impact of isolation precautions on HCPs. One survey of 28 HCPs in Spain demonstrated that some HCPs were concerned about an increased infectious risk while caring for patients under isolation precautions.[26]

In the lack of more concrete data, I submit that this specific kind of harm seems somewhat minimal and thus for the time being may be largely ignored. I do allow for the possibility to revisit this concern if future empirical data urges us to do so.

Against Vertical Strategies for Management in the Hospital

The main two arguments used to make my case in favor of horizontal over vertical strategies are utility, or beneficence in relation to the individual patient and family, and public health. Beneficence towards the individual patient means that HCPs should strive to optimize the patient's well-being. Going back to the Hippocratic oath, this is one of the normative pillars of medicine and is virtually accepted throughout. In recent years, beneficence has expanded towards the family, and HCP's are now expected to include the family in medical decision making. This inclusion stems from the realization that families generally know the patients best, and that patients wish to benefit their families, by way for example for including them in the medical decision- making process. This beneficence-based approach is often referred to as a patient- and family-centered approach.[20]

One of the strongest arguments limiting the scope of the utility argument relating to the individual patient draws its power from public health. Concerns related to the health of the public may outweigh concerns related to the individual. Prescribing an antibiotic for travelers' diarrhea for example may shorten the sickness duration by a few days, thus benefiting the individual patient. Prescribing antibiotics for a self-limiting disease however risks worsening antimicrobial resistance in the local environment, thus potentially harming public health.

In light of the aforementioned data, the argument against vertical strategies for MRSA management is straightforward. Espousing a patient- and family-centered care approach, utility to patients and relatives provides the main criterion to determine what is the right thing to do. In light of existing data- assuming that my representation and interpretation of the data so far is accurate- it seems that horizontal strategies for MRSA management are more effective in reducing MRSA transmission rates and overall prevalence (thus benefiting both current and potential carriers) and are less harmful than vertical strategies. If this is indeed the case, considerations of public health also align with such a patient- and family-centered care approach. Several caveats are in order.

First, the argument above obviously relies heavily on empirical data, such that if my representation of the data is inaccurate[5] or if novel, contradicting data are found, then my argument would weaken or fail altogether. For example, there is some proof that the nasal use of mupirocin is only effective in the short run and not in the long run, and that MRSA may acquire resistance to it.[3] In fact, my proposal here contradicts the following 2006 CDC recommendation:

"Because mupirocin-resistant strains may emerge and because it is unusual to eradicate MRSA when multiple body sites are colonized, do not use topical mupirocin routinely for MRSA decolonization of patients as a component of MRSA control programs in any healthcare setting. Category IB" [3]

Second, one should carefully distinguish the management of the asymptomatic carrier from that of the symptomatic carrier: moral arguments may apply differently to these two groups based for example on the degree of risk they confer on others. In other words, if symptomatic carriers pose a greater risk of transmission, isolation precautions in their case may be justified to a larger extent than in asymptomatic carriers. In making my general argument I loosely refer to these two groups as morally equivalent.

Third, one should also distinguish the management of the patient with a confirmed history of MRSA infection or colonization and that of the patient with current suspected or unknown infection of colonization. Again, these two groups may pose different risk and thus the normative argument above may apply to them differently.

Fourth, an add on to my argument above is the high prevalence of MRSA in the community as it is. Since MRSA is so common, one must weigh the harms of contact precautions against the long-term benefits to the individual patient and public health. If MRSA were less ubiquitous, considerations of public health then might outweigh considerations of harm and benefits to the individual patient, thus justifying contact precautions after all. Specifically, we would not want to expose families and other patients and staff to less common but highly resistant and thus lethal bacteria. This indeed may be the case for other resistant pathogens that are less common in the community, such as *Vancomycin-Resistant Enterococcus* and *Carbapenem-Resistant Klebsiella*.

Of course, one way to mitigate the harms caused by contact precautions has to do more with resource and personnel management, such as increasing the nursing staff.[23] Another way will be improving patient and HCPs' hygiene awareness and education.[23] Ideally, both these and horizontal strategies should be implemented to reduce MRSA incidence and prevalence.

A recent publication examining the benefits of contact precautions found no strong evidence in their support. The authors conclude that, "local factors, needs, and resources should drive the choice of optimal CP [contact precautions] utilization."[8] The current paper represents an attempt to demonstrate that ethical deliberations should drive the use of contact precautions. Such deliberations should account for the factors mentioned above and conclude with recommendations relevant to local contexts. Based on the discussion above, contact precautions for MRSA in general are hardly justified and should be reconsidered.

Conclusion

Management of MRSA in hospitals may include vertical or horizontal strategies. In this paper I review both strategies, demonstrating that horizontal strategies are most effective and safe. Based on these empirical data, I make a utilitarian case preferring horizontal over vertical strategies.

AUTHOR

Zohar Lederman, MD, PhD is a clinician and a postdoc fellow at the Medical Ethics and Humanities Unit, University of Hong Kong.

REFERENCES

1. Stevens DL. Chapter 124: Infections of the Skin, Muscles, and Soft Tissues.", edited by J. Larry Jameson, Anthony S. Fauci, Dennis L. Kasper, Stephen L. Hauser, Dan L. Longo and Joseph Loscalzo. In: *Harrison's Principles of Internal Medicine,*. 20th ed. New York: McGraw Hill.; 2019.

2. Davis KA, Stewart JJ, Crouch HK, Florez CE, Hospenthal DR. Methicillin-Resistant Staphylococcus aureus (MRSA) Nares Colonization at Hospital Admission and Its Effect on Subsequent MRSA Infection. *Clinical Infectious Diseases*. 2004;39(6):776-782. doi:10.1086/422997

3. Siegel JD, Rhinehart E, Jackson M, Chiarello L. Management of multidrug-resistant organisms in health care settings, 2006. *American Journal of Infection Control*. 2007;35(10):S165-S193. doi:10.1016/j.ajic.2007.10.006

4. Chen C-J, Huang Y-C. New epidemiology of Staphylococcus aureus infection in Asia. *Clinical Microbiology and Infection*. 2014;20(7):605-623. doi:10.1111/1469-0691.12705

5. Cooper B, Stone S, Kibbler C, et al. Systematic review of isolation policies in the hospital management of methicillin-resistant Staphylococcus aureus: a review of the literature with epidemiological and economic modelling. *Health Technol Assess*. 2003;7(39). doi:10.3310/hta7390

6. David MZ, Daum RS. Community-Associated Methicillin-Resistant Staphylococcus aureus: Epidemiology and Clinical Consequences of an Emerging Epidemic. *CMR*. 2010;23(3):616-687. doi:10.1128/CMR.00081-09

7. Lowy FD. F. D. Lowy. 2019. "Chapter 142: Staphylococcal Infections." In 20e, edited by J. Larry Jameson, Anthony S. Fauci, Dennis L. Kasper, Stephen L. Hauser, Dan L. Longo and Joseph Loscalzo. In: *Harrison's Principles of Internal Medicine,*. 20th ed. New York: McGraw Hill.; 2019.

8. Morgan DJ, Murthy R, Munoz-Price LS, et al. Reconsidering Contact Precautions for Endemic Methicillin-Resistant *Staphylococcus aureus* and Vancomycin-Resistant *Enterococcus*. *Infect Control Hosp Epidemiol*. 2015;36(10):1163-1172. doi:10.1017/ice.2015.156

9. Huskins WC, Huckabee CM, O'Grady NP, et al. Intervention to Reduce Transmission of Resistant Bacteria in Intensive Care. *New England Journal of Medicine*. 2011;364(15):1407-1418. doi:10.1056/NEJMoa1000373

10. Papia G, Louie M, Tralla A, Johnson C, Collins V, Simor AE. Screening high-risk patients for methicillin-resistant Staphylococcus aureus on admission to the hospital: is it cost effective? *Infect Control Hosp Epidemiol*. 1999;20(7):473-477. doi:10.1086/501655

11. Edmond MB, Wenzel RP. Screening Inpatients for MRSA — Case Closed. *N Engl J Med*. 2013;368(24):2314-2315. doi:10.1056/NEJMe1304831

12. Selvey LA, Antão C, Hall R. Evaluation of Border Entry Screening for Infectious Diseases in Humans. *Emerg Infect Dis*. 2015;21(2):197-201. doi:10.3201/eid2102.131610

13. Lederman Z. One Health and Culling as a Public Health Measure. *Public Health Ethics*. 2016;9(1):5-23. doi:10.1093/phe/phw002

14. Siegel JD, Rhinehart E, Jackson M, Chiarello L. 2007 Guideline for Isolation Precautions: Preventing Transmission of Infectious Agents in Health Care Settings. *American Journal of Infection Control*. 2007;35(10):S65-S164. doi:10.1016/j.ajic.2007.10.007

15. Cepeda JA, Whitehouse T, Cooper B, et al. Isolation of patients in single rooms or cohorts to reduce spread of MRSA in intensive-care units: prospective two-centre study. *The Lancet*. 2005;365:295-304.

16. Huang SS, Septimus E, Kleinman K, et al. Targeted versus Universal Decolonization to Prevent ICU Infection. *N Engl J Med*. 2013;368(24):2255-2265. doi:10.1056/NEJMoa1207290

17. Roth JA, Hornung-Winter C, Radicke I, et al. Direct Costs of a Contact Isolation Day: A Prospective Cost Analysis at a Swiss University Hospital. *Infect Control Hosp Epidemiol*. 2018;39(1):101-103. doi:10.1017/ice.2017.258

18. Wu PJ, Jeyaratnam D, Tosas O, Cooper BS, French GL. Point-of-care universal screening for meticillin-resistant Staphylococcus aureus : a cluster-randomized cross-over trial. *Journal of Hospital Infection*. 2017;95(3):245-252. doi:10.1016/j.jhin.2016.08.017

19. Sprague E, Reynolds S, Brindley P. Patient Isolation Precautions: Are They Worth It? *Canadian Respiratory Journal*. 2016;2016:1-5. doi:10.1155/2016/5352625

20. *The Joint Commission: Advancing Effective Communication, Cultural Competence, and Patient- and Family-Centered Care: A Roadmap for Hospitals.* Oakbrook Terrace, IL: The Joint Commission.

21. Roth VR, Longpre T, Coyle D, et al. Cost Analysis of Universal Screening vs. Risk Factor-Based Screening for Methicillin-Resistant Staphylococcus aureus (MRSA). Schildgen O, ed. *PLoS ONE*. 2016;11(7):e0159667. doi:10.1371/journal.pone.0159667

22. Kunori T, Cookson B, Roberts JA, Stone S, Kibbler C. Cost-effectiveness of different MRSA screening methods. *Journal of Hospital Infection*. 2002;51(3):189-200. doi:10.1053/jhin.2002.1247

23. Morgan DJ, Diekema DJ, Sepkowitz K, Perencevich EN. Adverse outcomes associated with contact precautions: A review of the literature. *American Journal of Infection Control*. 2009;37(2):85-93. doi:10.1016/j.ajic.2008.04.257

24. Stelfox HT. Safety of Patients Isolated for Infection Control. *JAMA*. 2003;290(14):1899. doi:10.1001/jama.290.14.1899

25. Tarzi S, Kennedy P, Stone S, Evans M. Methicillin-resistant Staphylococcus aureus: psychological impact of hospitalization and isolation in an older adult population. *J Hosp Infect*. 2001;49(4):250-254. doi:10.1053/jhin.2001.1098

26. Lupión-Mendoza C, Antúnez-Domínguez MJ, González-Fernández C, Romero-Brioso C, Rodriguez-Bano J. Effects of isolation on patients and staff. *American Journal of Infection Control*. 2015;43(4):397-399. doi:10.1016/j.ajic.2015.01.009

27. Seibert G, Ewers T, Barker AK, et al. What do visitors know and how do they feel about contact precautions? *American Journal of Infection Control*. 2018;46(1):115-117. doi:10.1016/j.ajic.2017.05.011

28. Lin Y, Barker E, Kislow J, et al. Evidence of Multiple Virulence Subtypes in Nosocomial and Community-Associated MRSA Genotypes in Companion Animals from the Upper Midwestern and Northeastern United States. *Clinical Medicine & Research*. 2011;9(1):7-16. doi:10.3121/cmr.2010.944

Clinical Ethics Informatics: An Initial Survey

John W. Frye III, PhD, MA

Abstract

Context: Ethics consultation in the US is widely used and reported in the literature, but multi-site comparison studies and data sharing across institutions are largely unknown or at least unreported. *Objective:* To better understand the different methods used by ethics services to record, taxonomize, analyze, and utilize data regarding their case consultations. *Design*: a 37-item questionnaire surveying persons who are "familiar with their ethics consultation database". *Participants*: A convenience sample of ethics service personnel recruited from several e-mail lists known to have ethics consultants among their subscribers. *Results:* A total of 53 unique surveys were completed. There was wide variety in institution's bed-size, consult volume, and ethics staffing among respondents. Recording practices for cases were similarly varied, with some institutions merely keeping paper documents with no analysis, others used spreadsheets with rudimentary analysis, and high-volume services employing specific programs or electronic medical record functions to provide a more robust analysis of various case features. The data recorded followed ASBH guidelines to varying degrees. Respondents reported a general desire for some standardization of recording methods and data types/inputs, which would be necessary before significant data sharing across institutions can be feasible or valuable.

Introduction

Healthcare ethics consultation is a service available in various healthcare settings that "seek[s] to resolve uncertainty or conflict regarding value-laden concerns that emerge in health care" such as patient rights, surrogate decision-making, and issues at the beginning and end of life.[1] Ethics consultation in hospitals has been practiced for over five decades.[2] Hospital ethics committees may perform a consultation function as part of their commitment to patient safety standards required by the Joint Commission on Accreditation of Healthcare Organizations that relate to the rights and responsibilities of the individual, to provide an ethical infrastructure to respect patient rights, values, beliefs, preferences, and decisions (RI.01.01.01 and RI.01.02.01).[3] Such committees also typically provide policy development, organizational support, and an educational resource for the hospital regarding various ethical questions.[4] At larger health-care institutions and systems, a single consultant or small team is more likely to take responsibility for addressing most ethics consultation requests.

Previous empirical studies of ethics programs at multiple locations, notably the 2007 study by Ellen Fox, Sarah Myers, and Robert Pearlman, have demonstrated two important findings. First, there has historically been substantial variety in the practice of ethics consultation at different institutions, in terms of consultant training/background, consultation model, case volume, methods of handling a consultation, and the integration of their role within the process of clinical decision-making.[5] Second, the strong show of support for such empirical studies, together with the large attendance at conferences across the country and the frequent use of e-mail lists to discuss issues of practice, demonstrate a widespread belief that ethics service personnel can significantly benefit their own practice by learning from other institutions.

As noted in the Fox study and elsewhere, almost all ethics consultation services keep internal records of their cases in their files. Here I shall use the term "database" to refer to the collection of such internal records, namely all documents and information kept by an ethics service for their own use and reference. This would not necessarily include a note placed in a patient's chart, as both the location of that note and its intent is directed at patient care. In contrast, the goals of keeping internal records include "improving performance, informing future consultation, legal purposes, and tracking workloads."[1] However, inasmuch as access to chart notes also provides for peer review and quality assessment and improvement,[6] a copy of such a note is a recommended addition to a service's database.[1] Some institutions may keep two separate sets of records: a collection of internal records of every case (each entry being a very detailed running description of actions by the consultant in text form), as well as a consult log (a spreadsheet that tracks minimal essential features of each case in brief).[7] Such databases represent a potential treasure trove of information regarding ethics consultation practice.

These databases have enabled the publication of dozens of single-site studies statistically analyzing scores or hundreds of ethics consultations, and more such studies have been presented at conferences. What is rarely attempted, however, is multi-site sharing and comparing of consultation data. At the time of this writing there has been no such published study to the author's knowledge. There have, however, been systematic reviews of single-site ethics consultation reports: one on ethics consultation in adult ICUs,[8] the other focusing on the typologies of ethical issues employed by ethics services.[9]

Several other practices, such as surgery and palliative care, have already taken cross-institutional data sharing to its logical endpoint and created national registries, high-volume databases of patient- and service-level information that enable significant research and quality improvement initiatives to proposed and pursued.[10,11] A national ethics consultation registry is at least a theoretical possibility. Consider that both ethics[12] and palliative care[13] have attempted Electronic Health Record (EHR)-based tools to prompt appropriate early consultation of their respective services, the latter having the additional resource of a national palliative care registry from which it could draw upon thousands upon thousands of cases nationwide to help design and refine its consult-prompting algorithm. A national ethics consult registry would provide unprecedented potential in being able to understand and shape the practice of ethics consultation throughout the US and beyond.

Clinical ethics informatics may be defined as the representation, processing, and communication of information present in and generated from the role of the clinical ethics consultant. When contemplating the feasibility of multi-site comparisons or a national ethics database, we are ultimately talking about how different services can record, analyze, and communicate relevant aspects of their own cases to others in a way that maximizes understanding and utility. Before attempting to understand how this might best be accomplished, one may first consider the current state of ethics services and their internal records that could form the basis for these projects. To that end, the following questions guided the formation and distribution of a survey focusing on ethics databases:

1. How are internal records kept?
2. What is included in these records?
3. What analysis is performed on these records?
4. How are standardization and sharing of consultation data viewed?

METHODS

A survey questionnaire addressing the key research questions was developed in discussion with others involved in ethics consultation and data recording at UCLA. The final survey contained 37 questions, 33 multiple choice and 4 short answer. Representative questions include:

"What kind of program do you use to record cases?"
"Does your database track any ethics service activities other than patient-related consultations? If so which?"
"What information about each patient is recorded?"
"What results do you obtain from your [data] analysis?"
"Would you recommend your database and analysis methods to other institutions?"

SAMPLE

A link to the survey was distributed through three e-mail lists: ASBH's Clinical Ethics Consultation Affinity Group (CECAG), the Medical College of Wisconsin's bioethics list (MCW), and the Southern California Bioethics Committee Consortium e-mail list (SCBCC). The recruitment e-mails requested that the survey be filled out by a person who was "familiar with their ethics consultation database." A convenience sample based upon those who replied from this list resulted in 54 surveys completed, 1 of which was a duplicate, resulting in 53 unique responses.

DATA ANALYSIS

The survey data was analyzed in Microsoft Excel using the Real Statistics Resource Package. The Fischer Exact test was used to test for differences in survey answers based on hospital bed size, consultation volume, and consultation approach (individual consultant vs small group). Spearman's rho was used to investigate relationships among ordinal variables including bed size, consultation volume, the year the consultation service started, how frequently the records were analyzed, and how much the analysis was automated.

RESULTS

Characteristics of Hospitals/Services:

The 53 responding ethics consultant services included a wide variety in how many beds their service covered (from 100 to over 1000), and in how many cases they handled per year (from fewer than 50 to over 500). **Results are depicted in Table 1 (below):**

When considering what these numbers actually report, and whether they can meaningfully be aggregated as assumed below, it should be noted that there is no agreed upon definition of what constitutes a single ethics consultation. In 2019 a survey conducted by Rebecca Yarrison strongly suggested that different services may count their number of consults in disparate ways, depending on whether they include informal consults (curbsides), how many ethical questions are present when first consulted, whether an issue recurs, whether later unrelated issues arise (both during or after the initial handling of the case), and whether a patient has been discharged and readmitted (Yarrison R., personal communication, 2019). Thus it may not always be meaningful to directly compare consult numbers from different institutions without understanding how they were arrived at. In my survey on ethics databases, 20 of 53 responding institutions (38%) reported that their consult numbers included curbsides, but no additional questions were asked regarding how they defined one unique consult in their records.

Bed #	100-199	200-299	300-399	400-499	500-599	600-699	700-799	800-899	900-999	1000+
	4	5	4	4	4	7	4	1	4	16

Case #	<50	50-99	100-149	150-199	200-249	250-299	300-399	400-499	500+
	13	9	11	6	3	2	1	5	3

Among all responses, there was a moderately strong correlation between the number of beds a service covered and consult volume (Spearman's rho = 0.475, p < 0.001). However, while this correlation was even stronger when looking only at respondents who counted curbsides as consults (rho = 0.671, p = 0.001, N = 20), it became non-significant for the respondents who did not count curbsides (rho = .177, p = 0.32, N = 33). There was significant variety in the ratio of consults to number of beds covered by a service as well, captured in the number of cases per 100 beds per year, which varied from fewer than 2 cases per 100 beds (a service covering over 1000 beds with fewer than 50 consults per year) to over 100 cases per 100 beds (a service covering 100-199 beds with 150-199 consults per year). **This data is depicted in Chart 1 (next page).**

Chart 2 (next page) shows how cases per bed per year varies with how many beds the ethics service covers. Across all responses, there were an average of roughly 24.5 cases per 100 beds per year. If we split the responses into those that counted curbsides versus those that did not, those that counted curbsides had a slightly higher average: 26.7 cases per 100 beds per year, compared with 22.9 cases per 100 beds per year among services that did not count curbsides as consults (however, this difference was not statistically significant).

Of the responding services, 62% used a single consultant model, while 36% used a small team approach of 2-4 persons, and 2% used a committee or subcommittee of 5+ persons. Compared to small

Chart 1:

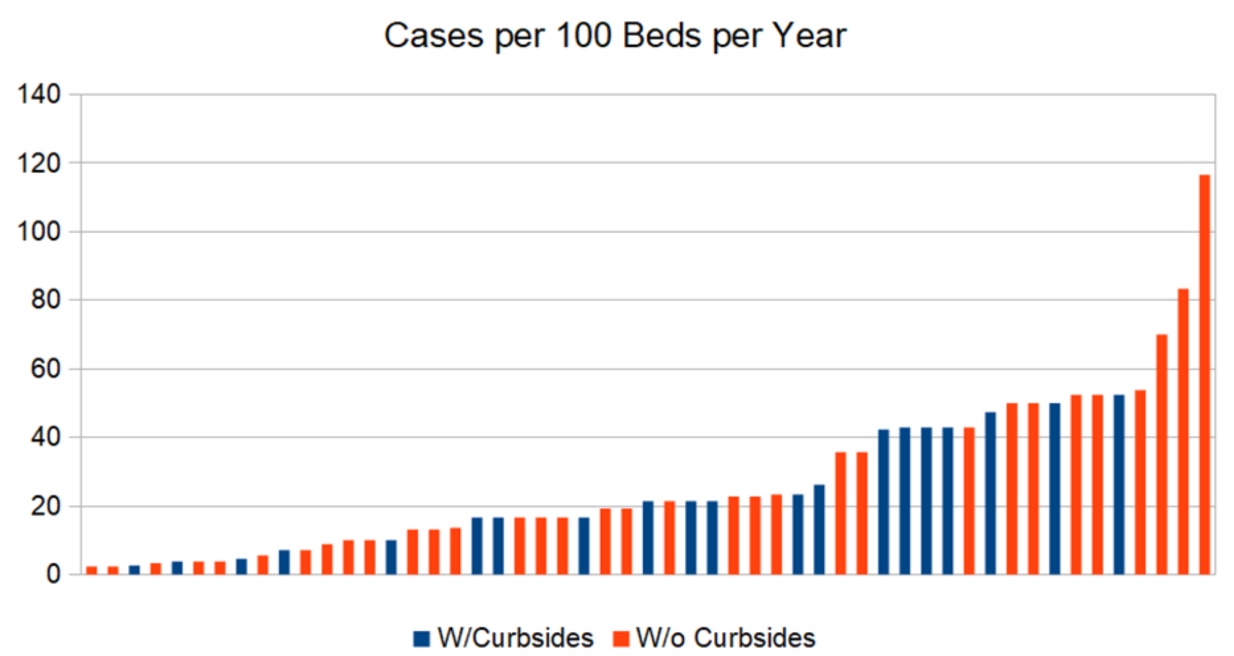
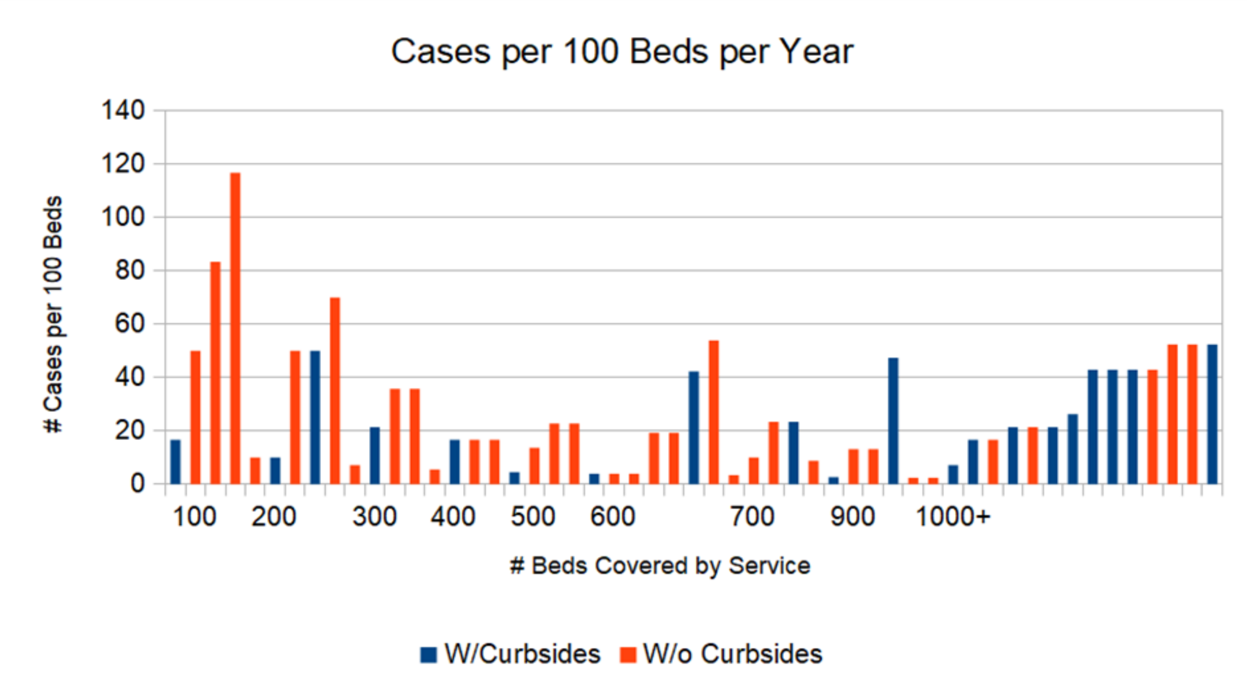


Chart 2:



teams, the single consultant approach was used in places with an average higher bed size, consult volume, and consult to bed ratio, although this difference was only significant with regard to consult volume. **Depicted in Table 2:**

	Single Consultant (n=33)	Small Team (n=19)	P value (T-test, one tail)
Beds Covered	736	636	0.15
Consult Volume	202	124	0.04*
Consults/100 Beds	30.2	22.2	0.14

Sixty-four percent of services would accept consults 24/7, while 17% only took emergency consults in the off hours, and 19% restricted consults to normal working hours.

General Characteristics of Databases

Eight ethics databases (15%) were initiated before 2001, the earliest in the mid-1980s. Nine (17%) were started in 2001-2010, 20 (38%) in 2011-2015, and 12 (23%) since 2015. (Note that ASBH provided guidelines for internal services records and what they should contain in the 2011 edition of the Core Competencies handbook.[3]) Twenty-four databases (45%) had been significantly revised since they were first initiated, five (9%) had been slightly revised, 23 (43%) had not been revised, and one respondent was unsure. In addition to record-keeping (96% of respondents), institutions frequently used their databases to assist in establishing frequency of ethical issues (79%), assess quality (62%), scholarly research (43%), petition for additional resources/staff (40%), establish consistency among consultants (38%), justify current resources (34%), and aid in education and resource allocation (17%).

The method for recording and keeping data also showed significant variance. Six services (11%) simply used Microsoft Word documents in a folder, and two (4%) had only paper records. The most common program to record data was a simple spreadsheet (32%), followed by EMR-based records only (19%), REDCap (13%), software specially designed for the institution (11%), and Access or other database management software (8%). Thirty-two institutions (60%) only used these internal records for consultation records, but other services also used the same database to record formal didactic sessions (21%), educational interventions (19%), policy formation efforts (19%), and community outreach (11%).

Forty-one respondents (77%) indicated that cases were recorded by the ethics consultant for each case, while 15% had a specific person who was tasked with all data entry, 4% used trainees or fellows for data input, and 4% would pull their data directly from patient electronic medical records rather than input data elsewhere. To ensure data is entered consistently, 34% of services train their consultants to enter their data properly, while another 8% have codebooks, 6% indicated they used templates to standardize entry, and 2% had two different persons review and crosscheck records. On the other hand, 26% of services had only one person enter all data into their records, and 13% indicated they had no method to ensure consistent data entry. Twenty-seven services (51%) reported recording all their cases in their internal records in the past five years (or since their database was started, if more recent), and 14 more services (26%) reported over 90% of cases were recorded. Five (9%) had documented between 75-90% of cases, six (11%) only had 50-75%, and one (2%) reported having less than 50% of cases in its records.

Database Contents

Table 3 (next page) shows the relative frequency of various consult-relevant information found in ethics services' internal records. Details included in at least 75% of databases include a patient's name, record number, age, location, and diagnosis; the position and concerns of the consult initiator, the date the consult began, and which the ethics consultant(s) responded.

Table 3

Patient information	%
Name*	83
Record #	79
Age	81
Other Demographic Information	58
Preferences/Interests*	28
Location*	87
Diagnosis/Medical Condition*	75
Capacity*	60
Code Status	60
Decision-maker*	62
Family Members Involved	58
Discharge information	36

Medical Team Information	%
Attending Physician*	57
Primary Care Team*	60
Services Involved in Patient Care	62
None	6

Requester Information	%
Name*	72
Position*	87
Contact Information	30
Requesting Service	62
Ethical Concerns*	91

Consult Details	%
Ethics Consultant*	85
Date Initiated*	96
Time Initiated*	32
Date Case Ended	42
Reason Case Ended	26
Hours/Minutes Worked	30
Whether Case Came in After Hours	11
Urgency of Case	34
Difficulty of Case	25
None of the Above	4

Consultant Activities	%
Review of Relevant Ethics Knowledge*	42
Formal Meeting Descriptions*	64
Summary of Ethical Analysis*	74
Identification of Surrogate*	55
Options Considered*	51
Explanation of Whether Agreement was Reached*	55
Recommendations/Action Plan*	74
Whether Ethics Note was Placed in Chart	58
Copy of Ethics Note Included*	38
None of the Above	2

Consultant Contributions	%
Clarified Ethical Issues, Options, Facts, Goals	72
Educated Participants about Ethical/ Policy Issues	58
Provided Support to Medical Team	62
Provided Support to Patient/Family	58
Addressed Conflict	64
Facilitated Communication	62
None of the Above	13

Following the Integrated Ethics approach,[14] in 2011 ASBH recommended over 20 items to be recorded in the service's internal records and included in patient records as appropriate, and that each service's internal records should include a copy of any notes placed in the patient's chart.[1] These were reflected in 22 questions in the survey **(marked with an asterisk in Table 2, previous page).** Each institution was given an "ASBH score" to reflect how many of the 22 items they recorded. The average ASBH score across all responses was 14.3. Only two respondents (4%) indicated they recorded all 22 items, and two institutions (4%) reported only recording three of the 22 in their databases. Nineteen institutions (36%) had 17 or more out of 22, while 13 institutions (25%) had 11 or fewer. ASBH recommended items that were recorded by fewer than half of respondents were patient preferences (28%), time the consult was initiated (32%), a copy of notes placed in the patient's medical record (38%), and a review of relevant sources of ethics knowledge [policy, codes, guidelines, precedents, etc.] (42%).

The ASBH scores of different databases did not significantly correlate with bed size, consult volume, or the year a service was initiated. However, institutions with more frequent data analysis were significantly more likely to have higher ASBH scores (Spearman's rho = 0.378, $p < .01$). Additionally, the small team approach was associated with a significantly higher average ASBH score than the single consultant model (16.4 vs 13.1, p = .013), though this may be an artifact of the data as the only ASBH item small team members were significantly more likely to record than single consultants was attending physician (78% vs 42%, p = .019).

Most services recorded some form of qualitative (text entry) information in their database, either in a separate field or as part of a copy of the patient's chart note included in their records. Such qualitative information likely related to the ethical issue (79%), the advice given (70%), case resolution (57%), and patient details (51%). On the other hand, 7 services (13%) did not record any qualitative information about a case in their databases, and 6 of those (11%) also did not include a chart note in their records.

Most services (57%) did not record any outcome measures in their databases. Those that did primarily noted conflict resolution (23%), clinical outcomes (21%), mentions of ethics in patient charts (15%), team satisfaction (13%), and family satisfaction (4%).

Content Analysis

A collection of data about case consultation enables one to analyze this data, for quality improvement as well as other potential benefits. Fifteen services (28%) did not routinely analyze their databases (including five that never analyzed it), while 13 (25%) did so only annually or less often. Fourteen services (26%) analyzed semiannually or quarterly, while 11 (21%) analyzed their cases monthly or more frequently. This variance may be related to the additional time investment that comes with analysis: the database records of 27 services (51%) did not provide any automated analysis. The programs used by 12 services (23%) provided simple analysis (defined as 1-4 results of note), while 7 programs (13%) provided moderate analysis (5-9 noteworthy results) and another 7 (13%) returned extensive analysis (10+ noteworthy results). The most common results were tracking which ethical issues commonly arose (89%), frequent sources of consults (74%), and trends in cases over time (68%). Less common were patient demographics (38%), work-hours (30%), frequency of ethics interventions (26%), caseload including average duration or difficulty (25%), and comparison of caseload between consultants (13%). Analysis results were commonly reported to the ethics committee (77%), hospital administration (58%), all ethics consultants (42%), and/or a department head/chair (36%).

Cross-Institutional Reflections

Only one respondent (2%) would recommend their database program/approach to other institutions in its current form. Five others (9%) would recommend theirs with some minor tweaks, while 18 (34%) said their approach should be customized to meet the needs of each individual institution. Twenty respondents (38%) would not recommend their database because they perceived it as having significant drawbacks, 8 (15%) responded that each institution should primarily respond to their own needs, and one (2%) indicated that databases are largely unnecessary. When asked about whether and why ethics databases may be important to a professional ethics consultation service, 96% indicated that database can help with consistency, quality assurance and improvement, 91% viewed databases as helping justify ethics consultation to one's institution as well as others, and 81% thought databases can help us understand the ethics consultant role. On the other side, 19% said that they may be somewhat helpful if only for administrative or legal reasons, 4% thought they take too much time away from other responsibilities, and 4% thought they missed too many essential components of ethics consultation.

Respondents were also asked about the possibility of cross-institutional comparisons. Seventy percent thought such comparison would help develop and standardize the profession of ethics consultant, 64% saw benefit for individual consultants and those who request consults, and 51% saw scholarly benefits. However, 6% thought such comparison would lose too much context to be worthwhile, and 4% thought it would take attention away from institutional needs.

Since such comparison requires a certain level of standardization, the survey also asked if there should be one standard way to record cases, and if the respondent would be willing to change their current database to be in line with a proposed standard. Two-thirds (66%) of respondents thought that a minimum standard would be best, allowing services to record additional information to meet their institutional needs. Perceived benefits of standardization included enabling more accurate and useful research and institutional comparisons (36%), ensuring professional standards for ethics are universally applied (29%), and helping with training and relocation (29%). Eight percent of respondents thought any attempt at standardization would make more problems or additional work than it would help address, 17% were against standardization, holding that each institution should respond to its own needs, and 2% thought records and standardization were both unnecessary. In terms of willingness to conform to a proposed standard, 52% said they would be willing to make substantial changes to their database to adhere to a proposed standard. An additional 11% would be willing to standardize provided only minor changes were necessary, while 23% would be willing to standardize but insisted they continue to record all the data they currently collect. Nine percent would only implement changes to meet the needs at their institution, while 4% thought their current method was appropriate and sufficient for their needs.

Discussion

This study reveals some important findings. First, internal records are useful to ethics services, as on average ethics services indicated their records helped fulfill at least 4 different purposes, notably including record-keeping, tracking the frequency of issues, quality assessment, resource justification/requests, and education. The real utility of a well-conceived and well-managed database is an important justification for ensuring cases are inputted promptly and completely, which otherwise could be perceived as a mere bookkeeping task with attendant low priority. Also, what is included in internal records is somewhat consistent with what ASBH has proposed.

There is general agreement that internal records can be an important resource, and that comparing data from such records across multiple institutions would be beneficial. Further, there is a desire for the standardization necessary to make such data-sharing possible, and a willingness to conform to standards that are proposed. This study has several important limitations. The data was collected from a convenience sample using an online form. Data was reported anonymously and in many cases may have been based upon the recollection of the respondent, which introduces a potential recall bias. Additionally, the survey was mostly multiple choice questions, some of which were forced choices between options that may not have obviously corresponded with the features of a particular database, or otherwise may have failed to capture the full range of possible responses.

Despite these limitations, this is the first study to report on the contents of a relatively high number of ethics consultation service internal records. The motivation behind this survey was to consider the feasibility, advisability, and desirability of using internal service records as a resource for cross-institutional research to better understand and standardize ethics consultation practices—to kick start the study and optimization of clinical ethics informatics. There are several challenges, however, to standardization and the possibility of robust and easy cross-institutional comparison, that this research has revealed or confirmed.

First, consultation services vary widely. There were large volume ethics services at relatively small hospitals, and services covering over a thousand beds that had fewer than fifty consults per year. This in part reflects the organic nature by which consultation services have arisen differently at different institutions. It will be hard to ensure comparisons are meaningful across institutions that have completely different hospital cultures, policies, laws, administrative structures, staffing, non-consultation activities of ethics services, and other contextual features.

Second, as this survey found, the programs and input methods that services use for their records vary widely, from paper to spreadsheets to web interfaces. Format, or at least type and method of data entry, need to be consistent if data can be meaningfully and readily shared and compared. This would mean both the definition and justification of a standard, as well as its voluntary adoption across many institutions. Importantly, what may work well and easily for consultants at one institution, say an analysis program heavily integrated into that institution's EHR, may not translate well to a universal standard, for several reasons (requires a particular EHR program, may require significant computer literacy or other training, etc.) Many institutions reported the use of simple spreadsheet files, either as a direct record or as a potential output file REDcap or whichever program they recorded cases in. This may provide a common format for sharing data at least, though the full scope of such considerations lies beyond this article.

Third, this survey found a wide variation in what kind of data is recorded, whether or how it is analyzed, even how to count different interactions as consults. These findings confirm and expand upon those of the 2019 systematic review of ethics typologies,[9] as well as a two-site study from 2011, which advocated a consistent list of well-defined terms in order to "increase professionalism, allow for easier consultation between ethicists, establish more consistent processes, and allow for research on HCE to be accomplished more readily."[15] This means having not just a single program (or small set of programs) for recording and sharing data, but at the very least a codebook defining important terms, and detailing the explanation and justification of variables that have measurability, applicability, and utility across institutions. This codebook and a training module would then need to be assessed for inter-rater reliability, both at single institutions and across institutions with significant differences in location, affiliation, size, resources, ethics services, etc.

Fourth, burdens, resources, and benefits are likely to be unequally distributed in any cross-institutional sharing arrangement. Users of a central ethics database may appreciate that many small institutions submit the handful of cases they see each year because it will better inform national metrics, trends, comparisons, etc. However, such a small institution may not itself benefit significantly from resulting findings of trends and resulting policy/educational recommendations regarding issues they do not see frequently, if at all. Alternately, it may be easier for a low-volume consult service to format and upload its handful of cases than a high-volume service that keeps records of its hundreds of cases each year in a format incompatible with a proposed standard. There were more than a few respondents who indicated that they were frustrated with keeping double books, or entering information merely to have it recorded somewhere, or that their database was cumbersome with slow input. We need to ensure that the benefit/burden ratio for most institutions is sufficiently acceptable that voluntary participation will occur.

Fifth, there needs to be a central body, presumably endorsed by or part of ASBH, that sets these standards, meets challenges such as deidentification, security, translation between input methods, and generally oversees any central database. Without a small, motivated group of persons committed to advancing the possibilities and goals of clinical ethics informatics, the idea of a common database for ethics consultations, as well as the feasibility of readily shareable consultation data, will probably remain simply an idea.

Clinical ethics informatics is not currently a field of research or intellectual inquiry beyond a scattered set of semi-isolated programs, languages, typologies, formats, and metrics that have been designed and used by the practitioners themselves for the sole good of individual institutions. There are vast uncharted possibilities for its future, and many significant questions to be addressed and challenges to overcome. Big data may not, and perhaps should not, impact ethics consultation the way it has many other clinical services; it is an untried tool with untapped potential. Time will tell what we make of it.

AUTHOR

John W. Frye III, PhD, MA studied mathematics and biology as an undergraduate at LMU, before earning a PhD in Bioethics from CWRU. His work in clinical ethics began in earnest during his post-doctoral fellowship at the UCLA Health Ethics Center. He currently splits his time as an adjunct professor of bioethics at CWRU, a clinical ethicist, and an independent consultant on QA/QI for health care ethics services.

REFERENCES

1. ASBH. Core *Competencies for Healthcare Ethics Consultation*. 2nd ed.; 2011. doi:10.5840/ncbq201818119

2. Kosnik AR. Developing a health facility medical-moral committee. *Hosp Prog*. 1974;55:40-44.

3. Joint Commission. Patient Safety Systems (PS). In: *Comprehensive Accreditation Manual for Hospitals*; 2018:PS1-PS50.

4. Hester DM, Schonfeld T. Guidance for healthcare ethics committees. *Guid Healthc Ethics Committees.* 2012:1-185. doi:10.1017/CBO9780511846441

5. Fox E, Myers S, Pearlman RA. Ethics consultation in United States hospitals: A national survey. *Am J Bioeth*. 2007;7 (2):13-25. doi:10.1080/15265160601109085

6. Dubler NN. The art of the chart note in clinical ethics consultation and bioethics mediation: Conveying information that can be understood and evaluated. *J Clin Ethics*. 2013;24 (2):148-155.

7. Bramstedt KA, Jonsen AR, Andereck WS, McGaughey JW, Neidich AB. Optimising the documentation practices of an Ethics Consultation Service. *J Med Ethics*. 2009;35(1):47-50. doi:10.1136/jme.2008.024265

8. Au SS, Couillard P, Roze Des Ordons A, Fiest KM, Lorenzetti DL, Jette N. Outcomes of ethics consultations in adult ICUs: A systematic review and meta-analysis. *Crit Care Med.* 2018;46(5):799-808. doi:10.1097/CCM.0000000000002999

9. deSante-Bertkau JE, Mcgowan M, Antommaria AHM. Systematic Review of Typologies Used to Characterize Clinical Ethics Consultations. *J Clin Ethics*. 2019;29 4:291-304.

10. Alluri RK, Leland H, Heckmann N. Surgical research using national databases. *Ann Transl Med.* 2016;4(20). doi:10.21037/atm.2016.10.49

11. Rogers M, Meier DE, Heitner R, et al. The National Palliative Care Registry: A Decade of Supporting Growth and Sustainability of Palliative Care Programs. *J Palliat Med.* 2019;22(9):1026-1031. doi:10.1089/jpm.2019.0262

12. Pavlish CL, Henriksen J, Brown-Saltzman K, et al. A Team-Based Early Action Protocol to Address Ethical Concerns in the Intensive Care Unit. *Am J Crit Care.* 2020;29 (1):49-61. doi:10.4037/ajcc2020915

13. Courtright KR, Chivers C, Becker M, et al. Electronic Health Record Mortality Prediction Model for Targeted Palliative Care Among Hospitalized Medical Patients: a Pilot Quasi-experimental Study. *J Gen Intern Med.* 2019;34 (9):1841-1847. doi:10.1007/s11606-019-05169-2

14. Fox E, Bottrell MM, Berkowitz K a, Chanko BL, Foglia MB, Pearlman R a. Integrated ethics: An innovative program to improve ethics quality in health care. *Innov J.* 2010;15(2):1 -36. doi:10.1163/9789047429937

15. Kekewich MA, Curran D, Cornick JL, Foreman TC. Mind the gap: The lack of common language in healthcare ethics. *J Clin Ethics.* 2011;22(3):261-266.

The Ethical Duty to Find Loved Ones of the So-Called “Unrepresented” Patient

Monica L. Gerrek, PhD, Oliver Schirokauer, PhD, MD,
Steven Radwany, MD, and Jane Penttila, JD

Abstract

An incapacitated patient without a surrogate poses a special problem for medical institutions. Such a patient is unable to participate in health care decision making and does not have a loved one to assist the health care team with this responsibility. This frequently means that the team, which is likely made up of complete strangers to the patient, is charged with making major health care decisions for the patient. It is understandable that significant attention has been given to how decisions should be made and who should participate in decision making for these patients. While these discussions are necessary and important, perhaps even more compelling is the ethical obligation medical institutions have to provide appropriate resources to find the loved ones of these patients.

Introduction

In the United States, there is a recognized approach to medical decision making when a patient lacks the capacity to participate and there is no record, such as a written advance directive, of the patient’s wishes regarding the decision at hand. Namely, the team is charged with trying to determine the patient’s relevant preferences by speaking with one or more surrogates who know the patient well and therefore can speak to what the patient would want. If there is no surrogate available and hence the patient is “unrepresented,” then decisions are to be made for the patient in accordance with what is deemed to be in the patient’s medical best interest.[1, 2] Implementing this last piece of guidance is not so simple, as these patients are in an especially vulnerable position, and numerous legal and ethical issues arise in conjunction with making medical decisions on their behalf. These concerns have not gone unnoticed in the literature. We direct the reader to Pope (2017) for an extensive description of the challenges associated with the unrepresented patient and various legal and institutional approaches to address them, to Kim and Song (2018) for a review of the rather sparse data-based literature concerning this topic, and to references 4-7 for a selection of additional analyses and recommendations.

Implicit in the decision making process just described is the assumption, which we adopt as uncontroversial, that the ethically appropriate way to proceed when a patient lacks decision-making capacity and there is no surrogate at the bedside, is to look for the patient’s loved ones, so that they have the opportunity to be with and care for the patient and, in particular, participate in decision making on behalf of the patient. Many of the articles cited above and included in Pope (2017) mention explicitly the need to search for loved ones when a patient is incapacitated and presents without a surrogate. Some emphasize the point by describing, or even recommending, steps that can be taken to find a surrogate.[2, 6, 8, 9] A topic, however, that appears to be generally unexplored in the literature is the extent of the ethical obligation which providers may have to look for a surrogate. In this paper, we consider the benefits and costs of dedicating resources to this effort and share our discovery that the potential rewards are far greater, and the burdens much lighter, than one might imagine. Our conclusion is that health care institutions have a clear and significant ethical duty to invest in looking for loved ones of apparently unrepresented patients, and to do so with a degree of dedication that is commensurate with the profound impact that a successful search can have.

Challenges for Hospital Staff

In this section, we describe how the Midwestern hospital with which we are associated responded to the challenges inherent in caring for incapacitated, unrepresented patients. Recounting this history affords an opportunity to identify a variety of concerns related to caring for these patients that we expect are shared by many institutions.

We begin with the obvious and practical problem of determining how to make medical decisions on behalf of a patient who cannot participate in decision making and has no surrogate. This concern, of course, comes with significant legal and ethical implications. From a legal perspective, there is a need for a clear process to be used by clinicians to establish that the tenets of informed consent have been adhered to as closely as possible. Ethically, there is a mandate in this situation to make decisions in accordance with the best interest of the patient, a task which is clearly fraught with uncertainty and which can be uncomfortable for those asked to perform it.[3]

In the early 2000s, in order to support staff and protect the hospital legally, our hospital developed a policy to guide decision making in this scenario. Hospital medical providers, the legal team, and the Ethics Committee (EC), in collaboration with the local Probate Court, formulated a policy in which three tiers of decisions were defined:

1. In **acute** cases, such as in the Emergency Department, physicians were required to document attempts to find a surrogate and proceed with care based on a best interest determination. A second opinion was considered helpful but was not required. This reflected traditional practice in urgent situations when a surrogate is not available, such as for patients with an acute, severe traumatic injury or a drug overdose.

2. For **subacute** situations such as when consent for an urgent surgery was needed, two or more medical opinions from different practice groups (if possible) were required. If the situation was less clear cut and the decision could be delayed, the policy required an urgent EC consult, with community and clergy participation on the EC to better represent the patient. In more **chronic** situations such as for placement in long term care, the policy required proceeding with guardianship application.

This policy proved to be effective. In particular, for difficult subacute cases, there was now a process in place that incorporated a range of perspectives into decision making and reduced the stress of providers caring for unrepresented patients. It also removed, in the subacute setting, the need to seek a surrogate through the courts and the associated delays in decision making. This change was especially meaningful in the case of terminally ill patients who might otherwise languish in the ICU. Of course, one consequence of the policy was that the EC now had significantly greater decision-making responsibility for patients who were incapacitated and unrepresented.

Over the ensuing years, several developments led to the EC playing an even larger role in decision making for these patients. Social work cuts in all hospital units coincided with a greater emphasis on length of stay as a core metric for the institution. Consequently, there were fewer staff available to find missing surrogates, at the same time that the pressure escalated to make decisions quickly. Due in part to these forces, EC consults for patients lacking capacity and without a surrogate increased steadily. In addition, the hospital's legal department began to have concerns that many subacute decisions were being made without adequate support, even when second or third medical opinions were obtained. Thus, they wished to prohibit any non-emergent decision for patients lacking a surrogate to proceed without the involvement of the EC.

As a result, approximately a decade after it was instituted, the policy was revised to mandate EC consults for all subacute decisions. The subsequent demand on the EC to convene to review cases and debate medical decisions was substantial. The workload, and the inefficiency of having the EC meet and deliberate only for family to arrive subsequently, as often happened, gave the committee great incentive to find loved ones up front.

Interestingly, during the same time period that the hospital system was implementing changes to its policy regarding incapacitated, unrepresented patients, its legal department was confronted with a new challenge. As the number of such patients being referred to the EC grew, not surprisingly, so did the number of unclaimed decedents filling the hospital's morgue. The need to arrange for disposition of these bodies led the legal team to search for family who could take responsibility for the decedent. Furthermore, the hospital's lawyers worked out an arrangement with the Probate Court that allowed the hospital to make disposition arrangements for unclaimed decedents, so long as an affidavit was prepared detailing the attempts to find family of the unclaimed. Thus, for some of the incapacitated, unrepresented patients who were referred to the EC, legal concerns about decision making made a thorough search for loved ones inevitable.

Finally, it is important to recognize the profound emotional strain that comes with caring for the incapacitated, unrepresented patient. Being responsible for, or even knowing about, critically ill patients who are alone throughout their hospitalization, without anyone to speak for them or pray for them or even just be present for their suffering, can be unspeakably sad. To their credit, we found that at our hospital, many employees – nurses, chaplains, aides, security personnel, secretaries – sometimes offered themselves during free hours just to be present for the patient and sit at the bedside, especially for patients thought to be dying.

In summary, the legal and ethical obligations around decision making, the financial environment, and the emotional toll of caring for patients who are alone and incapacitated all aligned to give the EC enormous motivation to look for loved ones. Two members of the committee, the hospital's clinical ethicist and the designated attorney representative, who had developed her detective skills searching for family of decedents, took on responsibility for looking for loved ones when the team at the bedside came up empty-handed. As we will see, the rewards for their efforts far exceeded all expectations.

Finding Loved Ones

In this section, we describe our experience with looking for loved ones of incapacitated, unrepresented patients. To assess the merits of investing time and energy into this endeavor, we address two questions. How much effort did searching require and, if loved ones were found, how often and to what extent did they want to be involved in the care of the patient?

The answer to the first question is that the amount of work required was relatively small. The two EC members who doubled as expert internet sleuths estimate that they succeeded in finding a family member in approximately 90% of the cases referred to the committee, and in most of these cases, did so within two hours. What is especially striking about this track record is that the cases that made it to the EC were the ones that had already been worked on by a social worker or case manager.

Perhaps even more surprising is what happened when loved ones were found. One might expect that an incapacitated, unrepresented patient would be estranged from family and friends, and therefore, that anyone discovered in a search would likely not be interested in participating in the patient's care or speaking on the patient's behalf. What we found, however, was quite the opposite. Time and again we saw that illness can bring families back together and that family members of sick patients will almost always participate in decision making, even when there has been an estrangement and regardless of the reason for the estrangement. Frequently, we found loved ones who were actively looking for the patient and would never have known about the patient's illness or death if not for our efforts. Ultimately, we came to believe that almost no one needs to be sick or die alone and learned to appreciate the mystery and magic in what appear, at first glance, to be broken relationships.

To give the reader a sense of our experience, we offer a few of the many moving stories we encountered in our searches for loved ones.

***Cousin on a Motorcycle*:** The patient was a 62-year-old male who had been found down at a homeless shelter. He had a very poor prognosis and the team was recommending hospice. However, he lacked decision making capacity and could not be enrolled in hospice because he could not give consent and had no family member present who could provide consent. When the EC was consulted about this patient, he had been in the hospital for five days, and the team had been unable to determine if he had family, let alone locate them. Neither a cursory search of his electronic medical record (EMR) nor a thorough search on the internet revealed any useful information. The next step was to look through the paper records that the hospital scans and keeps in an electronic archive that is separate from the primary EMR. About an hour into this search, we came upon a request for records related to a disability claim made two years prior to the current admission. This document was signed by a lawyer, whom we proceeded to contact. The lawyer would not provide any information but took ours. Several minutes later, we received a call from the patient's cousin, who lived 600 miles away, and who informed us that the patient was an only child, that his parents were deceased, that the two of them had been raised like brothers, and that he had been trying to reach the patient and his friends for days without success. After being advised of the patient's medical situation, he drove the 600 miles to the hospital during the night on his motorcycle to get to the patient's bedside. Once at the hospital, the cousin explained that he did not believe the patient would want to continue with life-sustaining measures given the poor prognosis. After his cousin consented, the patient was transferred to hospice. To our surprise, the patient's cousin was then able to find the patient's son, whom we had no knowledge of and who visited the patient in hospice before he died. If the cousin had not been found, the EC would have made a recommendation about the patient's treatment. It is likely that it would have been to withdraw life-sustaining treatment. Since enrolling the patient in hospice would not have been possible, he would have died alone in the ICU. Furthermore, the patient's cousin would not have known what had happened to his cousin. He expressed his deep gratitude to the team for finding him.

***Good Son, Bad Son*:** The patient was a 66-year-old male with a complex medical history who was admitted from home after being found unconscious by his home health aide. His prognosis was very poor, but neither the Medicaid waiver program he was involved in nor the Department of Veterans Affairs could locate family, although the waiver program believed he had two sons, "a good son and a bad son." A search of court records indicated that he had been previously married. Further review of court records revealed that he had assaulted his now ex-wife and that she had been treated at this same hospital for the injuries resulting from the assault. After receiving permission from our legal team, we searched the patient's ex-wife's medical records for contact information for possible children. We were able to find a phone number for a son. During a phone call with him, he advised that he was not the patient's biological son, but the patient's step-son who had ended his relationship with the patient. According to the step-son, the patient's other son, his biological son, was in prison for having assaulted the patient, and the patient had no other family. The step-son offered to come to the hospital and arrived shortly thereafter with his wife and his mother, the patient's ex-wife. After further discussion with the team, it was clear that the patient's step-son and ex-wife knew the patient well and despite the history with the patient expressed their desire to help him because they were his only family. They were able to act as appropriate surrogates and provided the team with information about what the patient's wishes would be in this situation. The patient subsequently died with his step-son and ex-wife at his bedside.

***Long Distance Ex-wife*:** The patient was a 72-year-old male admitted from an extended care facility with multiple acute problems and a very poor prognosis. The facility he had been living in was a forensic treatment center; he had been charged with trying to murder his second wife some years earlier. His violence was due to early onset dementia. The ICU contacted the EC three days after his admission because he was unrepresented and lacked medical decision-making capacity. His medical record did not provide any useful information. We checked the court records and learned the name of his first wife and that they had two children. A Google search revealed a LinkedIn page for someone with the same name as his first wife, working in Texas, some 1,500 miles away. We called the Texas workplace, explained the situation to the Human Resources representative, and left our contact information. Given the attitude of the representative, we had little hope of hearing anything back. However, the next morning, we learned that the patient's first wife had called the ICU overnight and had also left a voicemail for us. When we returned her call, one of the first things she said was, "We may be divorced, but he is the father of my children." She proceeded to begin the long drive, with her son, to our hospital. Unfortunately, the patient passed away before they completed the trip. Despite this, the family expressed their gratitude to us for finding them. Moreover, because we found them, they were able to talk to the chaplain who was with the patient when he died and know that he did not die alone.

Principles of Bioethics

It is often useful, when faced with questions of an ethical nature in health care, to refer to the framing principles introduced by Beauchamp and Childress: respect for patient autonomy, nonmaleficence, beneficence, and justice.[10] In this section, we move away from the anecdotal flavor of the previous sections and consider the benefits of finding loved ones for incapacitated, unrepresented patients in the context of the first three of these principles. We focus on the case that the patient is seriously ill, possibly near the end of life. Doing so allows us to introduce data that captures what patients care about at such a time. Based on our experience and sensibility, we believe the discussion that follows applies equally well when the patient's condition is not so dire.

Respect for Patient Autonomy**:** A primary reason to look for loved ones of incapacitated, unrepresented patients is to obtain input from them about the patient's wishes and values so that medical decision making can be guided by an understanding of what the patient would choose. Thus, the investment to find loved ones is directly tied to a desire to respect the patient's autonomy.

In addition, there is good reason to believe that the unrepresented patient would want a loved one at the bedside, at least at the end of life. We cite two studies. One asked a patient to rate the importance of various elements of the end of life experience.[11] We display six of these (the element, followed by the percentage of respondents rating the element as "very important"):

1. Saying goodbye to important people (90 %)
2. Resolving unfinished business with family or friends (86%)
3. Sharing time with close friends (85%)
4. Believing that family is prepared for one's death (85%)
5. Having family present (81%)
6. Not dying alone (75%)

In a second study, the authors asked patients with advanced cancer or some other end-stage diagnosis, staying in five hospitals in different regions of Canada, about care at the end of life.[12] The four most important concerns for these patients were:

1. To have trust and confidence in the doctor looking after you
2. Not to be kept alive on life support when there is little hope for a meaningful recovery
3. That information about your disease be communicated to you by the doctor in an honest manner
4. *To complete things and prepare for life's end (life review, resolving conflicts, saying goodbye)* (our emphasis).

We recognize that an incapacitated patient may not be able to participate in conversations with loved ones and that data from a study does not imply that a particular patient, perhaps especially one who is alone in the hospital, would choose to have loved ones present. However, these studies and what we have observed lead us to believe that it is likely that finding loved ones of a dying, incapacitated patient is congruent with the wishes of the patient. Given this to be the case, looking for loved ones can be viewed as an act of respect for patient autonomy.

Non-maleficence**:** The principle of nonmaleficence requires that providers strive not to harm their patients. Multiple investigations suggest that finding loved ones might have a protective effect on the quality of life and of death for seriously ill patients.

We begin with a study that found that incapacitated ICU patients who are unrepresented were in the ICU on average twice as long as those who had a surrogate and, in addition, that they received more life-sustaining treatments.[8] As the authors note, although more time and life-extending interventions in the ICU might reflect differences in medical status between the two populations, they may also be the result of decision-making delays or hesitancy on the part of providers to withdraw non-beneficial treatment when there is no surrogate to consent. In fact, the same authors, in a subsequent study with a larger group of collaborators, verify that some physicians are reluctant to consider withdrawal of life-sustaining treatment if no surrogate is present and draw attention to the wait that can be created by whatever decision-making process a hospital has adopted.[13] Though further research is needed, the concern is that when a dying patient has no surrogate, there is an increase in the likelihood that the patient's life will be prolonged by medical intervention with no expectation of improvement in quality of life. Such a death is referred to as *dysthanasia.* By contrast, finding loved ones for patients in the ICU can be part of an effort to allow for a natural death or *orthothanasia.*

Another study that supports this view is a retrospective investigation of patients who died in 146 Veterans Administration (VA) facilities providing acute or long-term care. It found that patients who had family involved in their care were more likely to have had a DNR order written than those patients for whom no family member participated in care.[14] This observation raises concern that unrepresented patients may be more likely than their represented counterparts to receive non-beneficial, potentially harmful, resuscitation near the end of life. We see again that loved ones at the bedside may play a role in safeguarding patients from dysthanasia.

Beneficence**:** Medical providers have an obligation to promote the well-being of their patients. What constitutes well-being for a patient approaching the end of life undoubtedly varies from person to person. However, the studies cited in the subsection on autonomy indicate that for most people, not being alone, having family present, and having closure with loved ones are of great importance and value.[11,12] If we embrace the notion that promoting these elements is in the patient's best interest, then the principle of beneficence urges us to make a concerted effort to find loved ones when a seriously ill patient is alone.

The retrospective of VA patients cited in the preceding subsection suggests that finding loved ones may offer an additional benefit to patients. Namely, it found that those who had family involved in their care were more likely to have had a palliative care consult placed and were more likely to have been visited by a chaplain than those for whom no family was present.[14] These practitioners address physical and spiritual suffering and in so doing provide care to patients and their loved ones that can be of great comfort and meaning to patients.

In this context, we note that finding loved ones can have a huge impact on the lives of the loved ones themselves. Heyland et al.[12] asked family members of patients with end-stage illness about what was most important to them. Six of the top eight concerns were related to the treatment that the patient was receiving. The remaining two were:

1. To have the opportunity to strengthen or maintain the relationship with your family member
2. To complete things, resolve conflicts, and say goodbye to your family member.

We see again the importance people place on connection to loved ones at times of serious illness. It is not our intent to explore the nature of the ethical obligation, if there is one, that a healthcare provider has to the loved ones of a patient. However, we do want to make clear that one of the great rewards of finding loved ones of sick patients, especially those who are dying, is the meaning and closure it gives to those who are found.

Finally, though the principles of bioethics are not generally thought of as guiding interactions between the hospital and its staff, it is important in the context of non-maleficence and beneficence, to recall the emotional distress that providers experience caring for incapacitated, unrepresented patients. The arrival of loved ones alleviates this sorrow and, as we have seen, can be truly uplifting. Thus, supporting the effort to find loved ones is one way that a hospital can care for its caretakers.

Conclusion

In this paper we have considered the fate of patients who lack medical decision-making capacity, have no surrogate, and are dealing with a significant medical condition. There are many such patients. In fact, one of the ICU studies cited in the previous section found that 16% of patients admitted to the medical ICU in a particular West Coast urban hospital over a 7-month period were incapacitated and had no surrogate for the duration of their admission.[8] The other ICU study cited above recorded that of all the ICU deaths that occurred over a 6-month period in seven hospitals located in the eastern and western U.S., 5.5% were deaths of incapacitated, unrepresented patients.[13] The numbers make clear that many lives are impacted by how hospitals decide to care for these patients.

At our hospital, as described, when the bedside team is unable to find a surrogate for an incapacitated patient, the case is referred to the EC. The committee, in turn, will continue the search for a surrogate and will only weigh in on medical decisions so long as these efforts fail. This practice of making an extra effort to look for loved ones began because of an interest in finding a surrogate to help with decision-making and thereby alleviate the burden on the EC. It has evolved into a profoundly rewarding component of care that goes far beyond decision-making. Bringing together loved ones who have lost each other is an opportunity to improve the quality of life for all involved and, in the case of patients who are dying, can allow for the possibility of a better death and a sense of closure. Given the evident benefits afforded patients, loved ones, and caretakers and the relatively small amount of resources needed to realize these benefits, we contend that health care institutions have a clear ethical obligation to ensure that they are investing adequately in finding loved ones.

This discussion naturally leads to consideration of the ethical obligation that providers might have to search for loved ones of unrepresented patients more broadly. For example, does a hospital have an ethical obligation to look for loved ones in the case that an incapacitated, unrepresented patient comes to the hospital with medical needs that are relatively minor? Or, expanding further, does a hospital have an ethical obligation to find loved ones for a patient who does have decision-making capacity and informs hospital staff that no family or close friends are in the patient's life? In this case, certainly a search should not be performed in the face of an autonomous refusal, but to what extent, if at all, does a patient have to actively support the idea of finding loved ones for it to be acceptable to begin looking? We do not attempt to answer these questions here but emphasize that there are many patients who are alone and whose lives and health could be improved by some creative searching.

AUTHORS

Monica L. Gerrek, PhD (co-author) is the Co-Director of the Center for Biomedical Ethics and Chair of the Ethics Committee at MetroHealth System in Cleveland, Ohio. She is also an assistant professor in the Department of Bioethics at Case Western Reserve University and serves as the clinical ethicist/educator at Summa Health in Akron, Ohio. While she is not sure ethics consultants or committees should be responsible for finding the loved ones of patients, she does believe hospitals have the obligation to do so. Playing investigator and reuniting families is one of the most rewarding things she does.

Oliver Schirokauer, PhD, MD (co-author) is an assistant professor in the Department of Bioethics at Case Western Reserve University in Cleveland, Ohio, where his responsibilities include overseeing the ethics curriculum for the medical students and co-directing the two-year Foundations of Clinical Medicine seminars program for the preclerkship medical students. He is also Director of the Medical Facilitation Program at the MetroHealth System. This program supports patients adjusting to major illness by helping them make sense of their circumstances and engage effectively in their care.

Steven Radwany, MD, FACP, FAAHPM is a Professor of Medicine in the Division of Palliative Medicine at the Ohio State University Wexner Medical Center currently focusing on providing palliative care to patients in the James Comprehensive Cancer Center. Previously he worked for 32 years as an internist and palliative medicine physician at Summa Health in Akron, Ohio where he served as Ethics Committee Chair for 20 years. His interests include clinical bioethics, postgraduate medical education, international palliative care, and program development in Hospice and

Palliative Medicine.

Jane Penttila, JD is a licensed attorney who worked in major health systems for 26 years prior to beginning a new chapter in life earlier this year. As a health care attorney, most of her time was focused on corporate legal matters. In addition, she has served on the ethics committees of these hospitals for the last 25 years. She readily admits that addressing patient issues and working with health care professionals provided the most personal satisfaction in her legal work, and sometimes the most frustrations.

ACKNOWLEDGEMENT

We would like to thank Njambi Kimani for the research assistance she provided.

REFERENCES

1. Karp N and Wood E. *Incapacitated and Alone: Health Care Decision-Making for the Unbefriended Elderly*. Washington, DC: American Bar Association; 2003.

2. Pope TM. Unbefriended and unrepresented: better medical decision making for incapacitated patients without healthcare surrogates. *Ga State Univ Law Rev*. 2017; 33(4): 923-1017.

3. Kim H and Song MK. Medical Decision-Making for Adults Who Lack Decision-Making Capacity and a Surrogate: State of the Science. *Am J Hosp Palliat Care*. 2018; 35(9) 1227-1234.

4. White DB, Jonsen A, Lo B. Ethical Challenge: When Clinicians Act as Surrogates for Unrepresented Patients. *Am J Crit Care*. 2012; 21(3): 202-207.

5. Pope TM. Making Medical Decisions for Patients without Surrogates. *NEJM*. 2013; 369(21): 1976-1978.

6. Smith ML and Luck CL. Desperately Seeking a Surrogate—For a Patient Lacking Decision–Making Capacity. *Narrat Inq Bioeth.* 2014; 4(2):161–169.

7. Farrell TW, Widera E, Rosenberg L, Rubin CD, Naik AD, Braun U, Torke A, Li I, Vitale C, Shega J, AGS Position Statement: Making Medical Treatment Decisions for Unbefriended Older Adults. *J Am Geriatr Soc*, 2017; 65(1):14-15.

8. White DB, Curtis JR, Lo B, Luce JM. Decisions to limit life sustaining treatment for critically ill patients who lack both decision-making capacity and surrogate decision-makers. *Crit Care Med*. 2006; 34(8): 2053-2059.

9. Moye J, Catlin C, Kwak J, Wood E, Teaster PB. Ethical concerns and procedural pathways for patients who are incapacitated and alone: implications from a qualitative study for advancing ethical practice. *HEC Forum*. 2017; 29(2):171-189.

10. Beauchamp TL and Childress JF. *Principles of Biomedical Ethics*, 7th edition. New York: Oxford University Press; 2012.

11. Steinhauser KE, Christakis NA, Clipp EC, McNeilly M, McIntyre L, Tulsky JA. Factors Considered Important at the End of Life by Patients, Family, Physicians, and Other Care Providers. *JAMA.* 2000; 284(19): 2476–2482.

12. Heyland DK, Dodek P, Rocker G, Groll D, Gafni A, Pichora D, Shortt S, Tranmer J, Lazar N, Kutsogiannis J, Lam M. What matters most in end-of-life care: perceptions of seriously ill patients and their family members. *CMAJ.* 2006; 174(5): 627-63.

13. White DB, Curtis JR, Wolf LE, Prendergast TJ, Taichman DB, Kuniyoshi, G, Acerra F. Lo, B, Luce JM. Life support for patients without a surrogate decision maker: who decides? *Ann Intern Med.* 2007; 147(1): 34-40.

14. Sudore RL, Casarett D, Smith D, Richardson DM, Ersek M. Family involvement at the end-of-life and receipt of quality care. *J Pain Symptom Manage*. 2014; 48(6): 1108-1116.

CASE 1

Professionalism: What’s Really Required?

The Editorial Group of the John J. Lynch, MD Center for Ethics

Complexity: 1 **2** 3 4

Abstract

Katherine Simpson is a first-year medical resident at Big City Hospital. Kenny Jay is a second-year surgical resident at the same hospital. Kenny starts talking about Katherine to his peers. He makes disparaging and vulgar remarks about her appearance, suggests that she’s too disorganized to be a physician and wonders out loud how she ever got through medical school. In a hospital (or physician practice or out-patient setting of any kind), it is critical to aspire to the highest levels of safety and mutual respect for patients and all others within the organization. Such an orientation is necessary to strengthen the moral climate of any health care institution which, in turn, supports moral decision-making by those within that environment. Thus, for the well-being of everyone around Kenny, his behavior needs to be checked, stopped, and redirected.

PRESENTATION

Katherine Simpson is a first-year medical resident at Big City Hospital. She lives with 3 other residents. Kenny Jay is a second-year surgical resident at the same hospital. There is a bar and burger joint, The Cow Barn, near the hospital where many of the residents go after their shifts. On one of these nights, Kenny runs into Katherine. She’s tired and just trying to get a quick bite to eat and go home. Kenny comes over and asks if he can sit down. Not pleased but afraid to seem unfriendly to one of the more senior surgical residents, she agrees. Almost immediately, Kenny starts hitting on Katherine. She’s immediately uncomfortable, gulps down her dinner, and gets up and leaves. This interaction is seen by several other residents who are also at the restaurant.

The next day, Kenny starts talking about Katherine to his peers. He makes disparaging and vulgar remarks about her appearance, suggests that she’s too disorganized to be a physician and wonders out loud how she ever got through medical school. One or two of the residents able to hear the comments also saw what happened the night before at The Cow Barn but are uncomfortable at the idea of saying anything to him about it.

Anthony (Tony) Knight overhears Kenny’s chatter, too. He knows Katherine and thinks she’s very smart, will make a great physician and is very concerned that Kenny’s comments will get back to her. He has spoken with her several times and knows she’s a bit shy and may lack the confidence to stand up to Kenny if she got wind of what he’s saying. Tony is also of the opinion that Kenny is arrogant and obnoxious. Worse still, Tony thinks Kenny is lacking empathy for his patients. Tony sees this lack of empathy spilling over into other personal interactions Kenny has with residents, finding his inappropriate and offensive comments about Katherine just part of the overall pattern.

Tony knows Kenny well enough to know that if he says anything to Kenny, directly, Kenny’s going to go after him. Any time Kenny feels threatened he goes on the attack and attempts to smear anyone who dares to suggest that he isn’t the greatest surgeon in the training program.

Tony is really torn. He feels that he wants to try and stop Kenny’s ranting about Katherine but is afraid of taking him on. He doesn’t want to go to the senior resident or his attending. In thinking it over, he remembers that in his orientation, the residents learned that there is an ethics program in the hospital, and they were told they could page any time. Tony had had the experience of having an excellent medical ethics course in medical school, having learned the ways in which a hospital’s ethics consultation service can be of help, confidentially, when ethics problems arise. Although this isn't an ethics problem about a patient, Tony intuitively knows that Kenny's behavior is wrong and harmful. He seeks out one of the clinical ethicists to discuss what might be useful next steps to begin to stop Kenny in his tracks and in so doing, maybe help Kenny to start down a path to becoming a better physician.

ETHICAL ISSUES

This case includes both interpersonal and organizational issues. Concerning the interpersonal, it is clear that somehow, Kenny's inappropriate verbal output about Katherine needs to be checked and stopped. It is harmful to Katherine, whether she knows it is occurring or not. And it forestalls in Kenny the kind of character development that ought to be required of every physician; this is a life-long process that if not already ingrained in a physician early in life, it is required once one takes the oath to become a physician. Right character is how a physician can be depended upon to attempt always to act in the best interest of his/her patients, colleagues, and society.

From an organizational ethics perspective, the practice of medicine is, in and of itself, a difficult and complex profession. In a hospital (or physician practice or out-patient setting of any kind), it is critical to aspire to the highest levels of safety and mutual respect for patients and all others within the organization. Such an orientation is necessary to strengthen the moral climate of any health care institution which, in turn, supports moral decision-making by those within that environment. Thus, for the well-being of everyone around Kenny, his behavior needs to be checked, stopped and redirected.

RECOMMENDATIONS

Over coffee, Tony and one of the hospital's clinical ethicists discuss what has been going on with Kenny, how Tony feels about Kenny and his behavior and what Tony might do. Between the two of them, Tony and the ethicist come up with an approach that might stop Kenny now and in future from making disparaging remarks about anyone, help Kenny understand that stopping this behavior is required by his training requirements, and help Tony feel more disposed towards Kenny, improving their working relationship. The decision was made that Tony would spend a little time by himself reflecting on how he feels about Kenny. As part of this self-reflection, Tony is going to try and think about Kenny the way he would about an unpleasant patient. For such a patient, Tony does not have any great difficulty mustering compassion for what the patient is going through and why the patient may be engaging in bad behavior.

Tony has also taught himself that once he has been able to depersonalize the situation, he tries to think compassionately about the patient. Perhaps this is a patient who has had a difficult life. Perhaps this patient comes from a dysfunctional family where interpersonal communications have always been rude, harsh, or demeaning.

Tony should try to engage Kenny in a light conversation about how impressed Tony is with the incoming residents this year. Of those he mentions, he is going to include Katherine (this approach will only work if Tony is indeed impressed and genuine in his praise). Then he's going to ask Kenny what he thinks about how the attendings depend on them to build confidence in the junior trainees and what might be good ways to do that, especially for those who seem a little shy, like Katherine. Tony should try to emphasize what he thinks Kenny does well, letting him know that others look up to him. Then Tony is going to cross his fingers and hope he has had some positive impact on checking Kenny's inappropriate behavior, preventing more of it, and helping Kenny look to his strengths and focus on those.

REASONING

At its most fundamental level, the approach Tony and the ethicist shape for Tony to take comes down to the idea that a positive and indirect approach will be more successful than taking a negative, punitive, 'in-your-face' approach. It is a way of addressing Kenny's bad behavior with a strategy that involves Kenny in his own character development and self-awareness. Having a conversation with someone with a plan to come to a certain conclusion is part of everyone's job. And doing it over a beer rather than in the hospital unit's conference room or someone's office is simply providing an environment that may be more conducive than having the conversation in the hospital. Setting is as important a consideration as is anything else; understanding that is not manipulative. It is simply being good at being effective in the work place.

What may seem manipulative is that Tony is thinking about and planning for the conversation rather than just having it. But this, too, is part of having successful conversations at work. Having a conversation at work, especially a conversation as important as this one (remember, there is a lot riding on this conversation; Katherine's wellbeing, developing self-awareness in Kenny of what is right behavior, and improving moral climate in the hospital), is not the same as having a conversation with your best friend. Work is work, regardless of where the conversation(s) takes place. And being always alert to one's responsibilities for conducting one's work conversations at a level of thoughtfulness is part of achieving excellence in interpersonal communication.

Achieving excellence in interpersonal communication, further, is not some mere nicety or old-fashioned physician etiquette. It is one of the Accreditation Council for Graduate Medical Education (ACGME)'s six Core Competencies.[1] These six are:

**Patient Care*
**Medical Knowledge*
**Interpersonal Communications Skills*
**Professionalism*
**Practice-Based Learning and Improvement*
**Systems-Based Practice*

The ACGME expects competency in all 6 areas to the level of a new practitioner. But even when these competencies have been considered met by the end of residency, these are the domains that make medicine a profession. From an ethical perspective, scientific and technical competency are only the baseline. Working to perfect these skills over the span of a career is the art of medicine. And it is mastery of the art of medicine that separates those physicians who are merely competent from those who are truly great.

Focusing only on the 'Interpersonal and Communication Skills' and 'Professionalism' domains, the ACGME Core Competencies spell out what skills and qualities are required. For mastery of the 'Interpersonal and Communications Skills' domain, the ACGME explains that residents must show skills in areas that, "…result in the effective exchange of information and collaboration with patients, their families, and health professionals." Residents must:

**communicate effectively with patients, families, and the public…across a broad range of socioeconomic and cultural backgrounds;*
**communicate effectively with physicians, other health professionals, and health related agencies;*
**work effectively as a member or leader of a health care team or other professional group;*
**act in a consultative role to other physicians and health professionals; among other requirements.*

In the ACGME 'Professionalism' domain, residents are called on to show, '…a commitment to carrying out professional responsibilities and an adherence to ethical principles." Residents must demonstrate:

**compassion, integrity, and respect for others;*
**responsiveness to patient needs that supersedes self-interest;*
**respect for patient privacy and autonomy;*
**accountability to the patients, society and the profession; and,*
**sensitivity and responsiveness to a diverse patient population.*

Kenny's behavior violates the ACGME requirement to communicate effectively with physicians, work effectively as a member of a team, and to show compassion, integrity, and respect for others. Rather than a skill, compassion calls on the physician to have the ability to imagine what another, who suffers, feels. This calls for a maturity in emotional response that allows the physician to empathize with the suffering of others.

REFERENCES

1. Kang, Danby, et al. "Are we meeting ACGME core competencies? A systematic review of literature on international surgical rotations." *The American Journal of Surgery* 216.4 (2018): 782-786.

CASE 2

End-of-Life? Dying? Does Our Assessment Change in a Pandemic?

The Editorial Group of the John J. Lynch, MD Center for Ethics

Complexity: 1 **2** 3 4

Abstract

In the middle of the COVID-19 pandemic, Mr. Smith had a heart attack. Just days before Mr. Smith's heart attack, the visitation policy was switched to a no-visitor policy, with the exception of a single visitor being allowed if the patient was at end-of-life. When Mr. Smith stabilized, the team's recommendation was to remove the ventilator and provide comfort care. Nevertheless, it seemed they were going to have to stick to the limited visitation policy, so his wife could not come in. Ought an exception be made so this patient's wife can come into the hospital prior to shifting a normal plan of care to comfort measures only? What does it mean to be at the end-of-life?

PRESENTATION

In the middle of the COVID-19 pandemic, Mr. Smith had a heart attack. He is 72 years old and diabetic but was otherwise fine prior to his cardiac event. Before the COVID-19 stay-at-home restrictions, he had been living an active life, playing golf twice a week, walking most of the course. Since the pandemic has set in, he has been walking 2-3 miles a day around his neighborhood with his dog.

Although the event was witnessed by his wife of 48 years and she tried to resuscitate him while the ambulance was on its way, she was not able to arouse him. When the emergency medical team arrived, they were able to obtain a pulse and intubated him in the field. He was transported to his local hospital, where he has been in the intensive care unit (ICU) for 4 days. Since all the area hospitals have implemented a no-visitor policy to protect against the spread of COVID-19, the EMTs informed Mrs. Smith that the doctors at the hospital would contact her promptly.

The treating team physicians have been keeping Mrs. Smith updated daily, although the news has been consistently grim. Although Mr. Smith remains COVID negative, it has not helped him. He has not awakened. He does not open his eyes nor respond to pain. The physicians believe he has suffered such a serious anoxic brain injury that he is not expected to improve. They are recommending that they remove the respirator and shift to comfort measures only.

Mrs. Smith has been open to that recommendation. Although she and her husband did not have Advance Directives (ADs), she has communicated that her husband was a very active person and she did not think he would want to survive if he would be completely dependent. However, Mrs. Smith would not agree to a shift to comfort measures only until she saw him.

About a week before Mr. Smith's cardiac event, the hospital had been allowing one visitor per patient, two visitors if the patient was at end-of-life. Just days before Mr. Smith's heart attack, with COVID-19 patients filling the hospital, the visitation policy was switched to a no-visitor policy, with the exception of a single visitor being allowed if the patient was at end-of-life.

In Mr. Smith's hospital, the process for designating that a patient is at end-of-life is the responsibility of the treating attending physician. That physician, once the end-of-life determination has been made, must contact either the Chief Medical Officer (CMO) or the Chief Nursing Officer (CNO) to obtain approval for visitation.

Permission to visit Mr. Smith was initially denied on the basis that the patient was not at the end of his life. However, as Mr. Smith's condition stabilized, the team's recommendation was to remove the ventilator and to provide only those interventions needed for the patient's comfort as he was expected to die quickly. Nevertheless, it seemed they were going to have to stick to the limited visitation policy to protect everyone from possible infection, so his wife could not come in. After the call to the CMO was over, Mr. Smith's attending called for an ethics consultation.

ETHICAL ISSUES

The ostensible ethics issue is about policy. That is, ought an exception be made to a policy that has been instituted to protect patients, healthcare providers, and others in the hospital from contracting COVID-19 so this patient's wife can come into the hospital to have the kind of discussion with her husband's healthcare providers that would be considered customary, prior to shifting a normal plan of care to comfort measures only.

Resolving this initially obvious ethics issue, however, is only the easiest of the ethics considerations at stake. Because the policy of no-visitors except for those patients at end-of-life was created to protect the vast number of patients and their families, this situation was not addressed specifically. When the clinical ethicist and the CMO discussed the ethical problem posed in this case, that is, the potentially coercive nature of the policy as written, it did not take very long for this consideration to result in the CMO reversing his decision by making an exception to that policy.

The deeper ethical aspect of this case surrounds what it means to be at end of life. Perhaps for a patient with metastatic disease that has progressed to the point where the patient is unresponsive, if her pain is sufficiently treated, it seems straightforward to say this patient is at the end of her life. She has an irreversible, progressive, terminal disease. Mr. Smith is representative of many patients with severe, irreversible brain damage of the sort that renders patients unresponsive except to pain, who cannot survive without life-sustaining technology of either a ventilator or a tracheostomy with a feeding tube. Often, with the application of such technologies, it is impossible to predict when death might occur, thus, coming to agreement on whether the patient is in an end-of-life condition presents a significant challenge.

RECOMMENDATIONS: What Does it Mean to be at End-of-Life?

Until orders for comfort measures only have been issued, the patient is unlikely to be considered at the end of life. Is the terminology of 'end of life' the same as, or sufficiently similar to, dying? In the example of a patient with metastatic cancer, given her advanced disease, many might agree that the patient is dying. It is likely that she meets hospice criteria for death within the next 6 months.[1] But in Mr. Smith's case and all the cases like him, there is sure to be disagreement.

Since originally conceptualized, the Surprise Question (SQ), "Would I be surprised if this patient died within 12 months?" gained quite a few adherents for its ability to be a clinical predictor of patient mortality.[2] Unfortunately, with enthusiasm for the SQ as a clinical tool to predict mortality in patients came additional research on its effectiveness, and findings for the utility of prognostic success in hospitalized patients have spanned from mixed to disappointing.[3]

It might be fair to suggest that Mr. Smith, at minimum, has had a terminal event. That we still know so little about brain damage makes it difficult, however, to say whether Mr. Smith's brain damage is irreversible or only possibly irreversible. If we cannot say that his brain damage is definitively irreversible, and in all other ways Mr. Smith is stable, many would be unwilling to say Mr. Smith is actively dying, or even in an end-of-life condition, ergo the original refusal to allow Mrs. Smith into the hospital. This clinical and philosophical problem begs the question of whether it is the same, or sufficiently similar to say that Mr. Smith is actively dying, dying, or at end-of-life. Fundamentally, these are conceptual matters, and how we define these terms, if carefully done, will carry practical implications regarding an assessment of appropriate care.

T.S. Eliot said "In my beginning is my end." [4] Although Eliot may have been correct in the broadest sense of human existence; that as soon as we are born we begin to die, engagement with this expansive possibility is well beyond the scope of this case discussion. Even more narrow medical questions about whether Mr. Smith, and the many patients like him, are actively dying, dying, and/or at the end-of-life are also beyond the scope of this case to explore. Nonetheless, they have been noted as the deep, fundamental questions to which philosophers who wish to assist clinicians and clinical ethicists should give much more attention than they have to date. Given, however, that a central difference between ethical theory and applied ethics is that the latter focuses on arriving at the ethically optimal (or at the very least, ethically permissible) solution to a particular clinical problem for a particular patient within a particular time frame, we return to the specifics of Mr. Smith's case and the last clinical ethics issue to resolve.

When Mrs. Smith comes to see her husband and have an end-of-life conversation with her husband's physicians, she decides that although she still believes her husband would not want to be sustained for a prolonged period in a dependent state, he also would not want to quit too soon. With her husband's physicians unwilling to even say that Mr. Smith is dying, shifting to comfort measures now, for Mrs. Smith and what she believes her husband would want, would be too soon. And if Mr. Smith is going to be given more time, he will have to be trached and pegged.

Perhaps the best way to frame this for best practices in clinical ethics is that if physicians are willing to say a patient is actively dying, life-extending procedures not intended to only provide relief of pain and/or suffering ought not to be offered or provided. But if a patient's physicians believe that they can make a patient stable for discharge, even while the debate rages about what it means to be actively (or imminently) dying, dying, or at end-of-life, as long as there is no consensus in the US about the appropriateness of the use of life-extending technologies under such conditions of uncertainty, a decision to choose between a shift to comfort measures only or agreeing to provide life-extending technologies is left to the patient's family, unless the patient has left clear ADs to the contrary.

Even though there are some First World countries, most notably France, where next steps for a patient in Mr. Smith's circumstances would likely be left to physicians, this is not the case in the US.[5] In the US, if the family wants more life-extending technologies in the face of physicians unwilling or unable to assess Mr. Smith as actively dying, the patient would have these procedures and he would be moved to a long-term care facility where the family could visit while they waited to see if he improves or if they should, at some point in the future given Mrs. Smith's belief that her husband would not want to be sustained indefinitely in a dependent state, be shifted to comfort measures only.

But these are not ordinary conditions. Mr. Smith has found himself hospitalized in the COVID-19 pandemic. Of course, the longer he stays in the hospital, the more at risk he is of being infected with coronavirus 19 but so far he has not. With Mrs. Smith unwilling to shift to comfort measures only, the choice is being made by indecision - the hospital will not shift to comfort measures over the objection of family, in a patient who is sufficiently stable to be made ready for discharge. And if a patient finds him or herself in a situation where there is no societal consensus that someone in Mr. Smith's condition is considered to be actively dying, the decision will default to trach and peg.

REASONING:

Do Conditions of a Pandemic Change This Moral Calculus?

Given the pandemic, the added ethical wrinkle is that the patient won't go anywhere different, except from an ICU bed to a bed on a regular floor. Although the hospital has moved everything around to expand surge capacity for COVID-19 positive patients, there are beds on the floor that could take Mr. Smith. So far, this particular hospital has not been overrun with COVID-19 patients. The difference is that neither Mrs. Smith nor any of the Smith's adult children can come and visit.

Mr. Smith, now trached and pegged and on the floor, is just as stable as before. Whether one would consider him dying and/or end-of-life, he is definitely not *actively* dying. Mrs. Smith has accepted the policy that once the exception was made, if this was her choice, she would not be allowed back to see Mr. Smith again. Since there are no long-term facilities in the surrounding area that will accept any new residents, Mr. Smith is stuck in the hospital. At a point at which this hospital might be overrun with COVID-19 patients, one might have to revisit this case given that Mr. Smith is holding a bed. The issues will be the same, all over again. But for now, the clinical ethics complexities have been resolved. There will be no ethical issue about Mr. Smith being in the ICU, using a precious ventilator that perhaps might be used more successfully by a patient who could survive going back to a normal and full life. Mr. Smith will continue to force us to ask ourselves whether Mr. Smith is dying and/or at end-of-life. And Mr. Smith, and patients like him, will continue to force our society to define these terms clinically in ways that can produce theoretical and public policy consensus.

REFERENCES

1. Fine PG. Hospice underutilization in the US: The misalignment of regulatory policy and clinical reality. *J Pain Symptom Manage*. 2018 Nov;56(5):808-815.

2. Moss AH, Ganjoo J, Sharma S et al. Utility of the “surprise” question to identify dialysis patients with high mortality. *Clin J Am Soc Nephrol* 2008;3:1379-1384

3. Downar J, Goldman R, Pinto R, Englesakis M, Adhikari NKJ. The “Surprise Question” for predicting death in seriously ill patients: A systematiac review and meta-analysis. *CMAJ*, 189(13), E484-E493. 2017 Apr 3.

4. Elliot, T. S. *Collected Poems 1909-1962*. Faber & Faber, 1974.

5. Baumann A, Audibert G, Claudot F, Puybasset L. Ethics review: End of life legislation – the French model. *Critical Care* 2009, 13:204.

CASE 3

Medicating Against Objection for Safe Psychiatric Discharge

The Editorial Group of the John J. Lynch, MD Center for Ethics

Complexity: 1 2 **3** 4

Abstract

Mr. R is a 38-year-old male who was admitted to the involuntary psychiatric unit at Midwestern Medical Center, a process that authorizes immediate involuntary commitment of an individual if that individual is mentally ill and likely to injure self or others. Mr. R stated that there was no justification for him to have been admitted. As his voice became increasingly elevated, the unit staff became concerned about a potentially violent outburst. Dr. Hurst felt that it would be in Mr. R's best interest to receive medication against objection. Mr. R's consistent refusal to accept medication created a circumstance in which the psychiatric team is now limited in what interventions would be appropriate even if just enough for discharge. At that, 'just enough' would likely be insufficient to assure Mr. R's return to his community *safely* and with a clear willingness to maintain his medications as prescribed.

PRESENTATION

Mr. R is a 38-year-old male who was admitted to the involuntary psychiatric unit at Midwestern Medical Center, a process that authorizes immediate involuntary commitment of an individual by someone who has a reason to believe the individual is mentally ill and is likely to injure self or others as a result of that illness. The individual can be transported to a hospital for psychiatric evaluation. Based on the evaluation, the individual may be released, detained for treatment, or hospitalized.

Mr. R was found by police outside of the city courthouse making threats to the staff entering and exiting the building. When police were called to the scene, Mr. R was evasive and resistant, shouting that the city's judicial system had violated his rights, and that the prime minister of Malaysia had communicated to him through email that he had a job for him so long as he could handle his legal issues at home, first. Given his threatening behavior and what the police assessed to be an unpredictable state of mind, he was detained and transported to the inpatient unit.

After completing a psychiatric evaluation, it was determined by Dr. Hurst that Mr. R should be kept and treated with the aim of stabilization sufficient to assure the medical staff that he could be discharged safely. Psychiatric evaluation and a review of Mr. R's medical records revealed the possibility of schizoaffective disorder and a history of delusional thoughts and behavior. After spending the first night in the unit, Mr. R appeared much calmer. Nevertheless, when approached about the reasons he was admitted and Dr. Hurst's recommendation that he would need to begin taking medication in order to be safely discharged, Mr. R became argumentative. He stated that there was no justification for him to have been admitted against his will in the first place, and that he had proof of the conversations with the prime minister of Malaysia, demonstrating that despite his medical history, these events were real. As his voice and behavior became increasingly elevated, the unit staff became concerned about a potentially violent outburst and Mr. R was escorted to his room, where he remained isolated for a short period. Dr. Hurst came to Mr. R's room and again, quite calmly, attempted to explain to him that without agreeing to medication, he would not feel alright about discharging him. Mr. R was again adamant that he would not be accepting any medication and he wanted to be released. At this stage, Dr. Hurst felt it was necessary to initiate a medication review process to reach a consensus with Dr. Hurst's colleagues that it would be in Mr. R's best interest to receive medication against objection. A medication review would likely result in allowing the staff to administer the medication, despite Mr. R's refusal. Once Mr. R was again amongst the other patients in shared space, he requested a phone call, stating "I'm calling the hospital ethicist because my rights are being violated."

The ethicist on-call spoke with Mr. R, who asked if he could speak to someone in person. The ethicist agreed and went to the impatient unit to speak with Mr. R. During their conversation, Mr. R appeared calm and well-spoken in articulating his thoughts, however, none of the issues he insisted on discussing had anything to do with why he had been admitted, nor did he appear to impress upon the ethicist that he was in any way willing to change his mind about taking medication. Most of the conversation regarded his emails with the prime minister of Malaysia, claiming that medications have never helped him "in all the institutions I've been in." Uncertain that the present discussion would result in Mr. R agreeing to take the medication, the ethicist did his best to appeal to Mr. R's pattern of reasoning while explaining that the medication would be in his best interest, should he value being discharged safely to the community. Mr. R finally agreed to consider taking the medication, and the conversation ended.

ETHICAL ISSUES

Although Mr. R was able to conduct reasonable conversations when he chose to do so, it became clear that he may be, at least in his present circumstances, prone to violence and likely to either injure himself or others. The legal process allowing the hospital to hold Mr. R against his will not only appears warranted, but his consistent refusal to accept medication created a circumstance in which the psychiatric team is now limited in what interventions are both appropriate and could assist in stabilizing his behavior, even if just enough for discharge. At that, 'just enough' would likely be insufficient to assure Mr. R's return to his community *safely* and with a clear willingness to maintain his medications as prescribed.

RECOMMENDATIONS

1. Attempt one last time to speak with Mr. R post-discussion with the ethicist, since it appeared at the end of that conversation Mr. R would take the time to consider accepting the medication. Have the conversation preferably conducted by someone on the psychiatric unit who has not yet lost Mr. R's trust, or with whom he has not experienced conflict.

2. If Mr. R continues to refuse medication, or shows any other signs of potential violence or injury to himself or others, ethics recommends psychiatry move forward with the medication review which will likely result in a decision to medicate Mr. R against his will.

The ethicist entered a progress note into the patient's chart in which he included his recommendations as listed above. However, over the weekend, the ethicist read in Mr. R's medical record another progress note from Dr. Hurst indicating that Mr. R had been violent with a fellow patient on the unit, and that he was restrained in light of the event. Moreover, that the medication review was moving forward.

REASONING

When a review panel for medication against objection, or what may be referred to as being medicated against one's will, is suggested, what is being sought is a direct intervention for a patient that goes against that patient's expressed preference to forgo psychiatric medication. This is quite different than considering the position of a surrogate in cases in which a medical patient lacks decisional capacity. In those cases, a surrogate must first consider what the patient *would* want if the patient had not executed some form of Advanced Directive (AD). In the case of Mr. R, what the patient wants is being expressed clearly and a separate avenue for justification for intervention is being sought external to the patient or anyone assigned to represent him. This is a peculiarity of many involuntary psychiatric commitment procedures.

Ethically, medicating even an involuntarily committed psychiatric patient should constitute a last resort for scenarios in which the risks involved in not medicating are significant. That does not mean that potential negative consequences ought not be considered as in any medical intervention, e.g. the potential negative consequences of damaging trusting relationships between the patient and others in the medical profession and constraining a patient's autonomy.

In psychiatry, this problem, i.e. either potentially traumatizing a patient by forcing involuntary treatment and breeching a patient's autonomy or allowing the patient to go untreated, risking further decompensation has a long history.[1] Further, this mostly unhappy history in psychiatric care is entangled with criminality and police systems. We get the word 'bedlam' from the world's most well-recognized psychiatric asylum, London's Bethlem Royal Hospital, established in 1307. As time passed, such custodial institutions were established around the world.

To most in contemporary psychiatric care in the United States (US), the deinstitutionalization movement in the US began in the 1960's and in 1963, President John F. Kennedy signed legislation that was to create the community safety net for the psychiatrically deinstitutionalized.[2] Unfortunately, that safety net was never created to the extent needed and so many of our psychiatrically ill citizens are incarcerated or homeless on city streets.

As the shift from institutionalization to discharge was occurring, so were changes in the laws concerning treatment for the mentally ill consistent with the ascendance in the law and the new field of bioethics of preferencing autonomy over beneficence. The convergence of these three social changes resulted in the kind of case we see with Mr. R.

Mr. R is not only lucid but articulate in his not-capacitated refusal of psychiatric medication. The medical and ethical complexity that causes for a psychiatric patient admitted to an inpatient unit for involuntarily committed patients in a hospital, is that there are multiple influences, judicial, social and financial, that put pressure on the psychiatric care team to get Mr. R released. Thus, minimally treating Mr. R so he is recovered 'just enough' to be discharged, supported by the mounting data that psychiatrically ill patients who are treated over their objection will not continue on a recommended treatment regimen once discharged virtually assures that meeting the 'just enough' treatment threshold has a higher likelihood of negative versus positive outcomes of his hospital involuntary commitment.[3,4]

In Mr. R's case, as already mentioned, unfortunately, it is most likely that this patient will be medicated over his objection. But it can be hoped that once he is discharged, given especially that this patient seems articulate and able and willing to consider other avenues of care, he might follow up with outpatient psychiatric care.

If this could be accomplished, perhaps the best hope Mr. R has for avoiding this situation again is to draft and sign a Facilitated Psychiatric Advance Directive (F-PAD), sometimes referred to as a Ulysses Contract. The F-PAD has been developed to be an effective tool for reducing the use of coercive interventions in mental health crises with psychiatric patients who are decisionally lacking capacity. The study cited by Swanson and colleagues demonstrates the promise of these documents to increase the prospect for honoring the capacitated wishes of a patient during a psychiatric crisis and even possibly reducing involuntary commitments. If the promise holds up, that would be a great advance for the care of the psychiatrically ill. Perhaps Mr. R could be cared for in such a way that once well enough, he can be helped to complete such documentation so the trajectory of his next decompensation might be different.

REFERENCES

1. Saya A, Brugnoli C, Piazzi G, Liberator D, Di Ciaccia G, Niolu C, Siracusano A. Criteria, procedures, and future prospects of involuntary Treatment in psychiatry around the world: A narrative review. *Front in Psychiatry*. 2019:10:271.

2. Testa M, West SG. Civil commitments in the United States. *Psychiatry* (Edgmont) 2010; 7(10):30.

3. Bonsack C, Borgeat F. Perceived coercion and need for hospitalization related to psychiatric admission. International *Journal of Law and Psychiatry*. 2005;28:342-347.

4. Swanson JW, Swartz MS, Elbogen EB, Van Dorn RA, Wagner HR, Moser LA, Wilder C, Gilbert AR. Psychiatric advance directives and reduction of coercive crisis interventions. *J Ment Health*. 2008 Jan 1:17(3):255-267.

JOURNAL OF HOSPITAL ETHICS **Volume 7, Number 1**

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

Non-Profit
Organization

U.S. Postage
PAID

Washington Hospital
Center