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Communications: "But Nobody Told Us!"

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ROUNDING WITH THE EDITOR

Variability

Evan G. DeRenzo, PhD

Dear Readers,

Welcome to Volume 8, Number 3 of the Journal of Hospital Ethics (JoHE). As I look over the works in this issue, something jumps out at me. There is a through-line across many of these pieces: variability and attempts to reduce it. In one way or another, many of the articles and cases in this issue, whether explicitly or in a less direct way, raise the issue of complexities produced by variability.

Variability, or more accurately, ways to reduce variability, has been an on-going discussion in the Lynch Center since I arrived almost 24 years ago. We would talk frequently about the threats posed to the quality of ethics consultation and to building respect among hospital clinicians and administrators for ethics consultation, by not reducing variability across consultants. These conversations would be weighed down seemingly by the fact that no matter how hard we tried, each of us were different individuals with differing personalities, consultation styles, training and experiential backgrounds, and these differences were not to be surmounted.

But the concern was never extinguished and so the group, always highly collaborative, would come together several times a week, daily if needed, to talk about cases that we were facilitating to make sure that our general approaches were considered up-to-snuff by the rest of us.

More recently, we have added to that habit a more formalized weekly meeting in which our notes and consultation techniques are reviewed by the group. Most recently we have begun using REDCap. REDCap (Research Electronic Data Capture program) is a web-based application, developed at Vanderbilt University, for use in the development of databases in medicine for research and project development.¹ We use REDCap to track that our notes all include certain pieces of information to meet a minimum consistency across clinical consultations, and in the hope that one day we will be able to conduct research across centers in the US devoted to Clinical Bioethics in the hope of gaining insights to further reducing variability in ethics consultation.

A quick look through PubMed, a primary database for medical journal literature, turns up many examples of efforts to reduce variability from disparate medical specialties. One sees research regarding nurses attempting to reduce staffing variabilities that produce nursing stress.² Variability in the pharmacokinetics of anti-cancer drugs is seen as slowing down the promise of translational medicine.³ Even more recent literature addresses the seemingly impossible challenge of regulating emotional variability.^{4,5}

Perhaps the richest literature on attempting to improve outcomes by reducing variability has been in surgery. One of the most far-reaching examples is of the introduction of checklists for patient safety.⁶ Known as the Keystone Project, this study produced positive results that encouraged the rapid and widespread introduction of checklists in surgery. Thereafter, however, studies produced mixed results, finding that checklists may not be producing increased benefits as compared to surgery without such checklists, throwing cold water on the checklist endeavor in surgery.⁷

That was until the meticulous introduction, punctilious analysis and intense study of the World Health Organization's (WHO's), Surgical Safety Checklist.⁸ The WHO's checklist was altered in strategically structural ways. In its study, the WHO's checklist's implementation was rigorous. In its early evaluation, important positive findings emerged.⁹ The findings were so promising that the enthusiasm that had been dampened about the original Keystone Project's checklist data has returned.^{10,11}

Which brings us back to reducing variability in medical ethics. In an effort to assist spinal cord injury patients making a successful transition from the ICU to rehabilitation after ileostomy placement, a condition-specific checklist has been developed, tested and studied.¹² Here too, positive findings supported the use of a checklist related to study parameters. It seems that checklists are here to stay since, if done well, they help patients, and these benefits serve clinicians and hospital administration.

As with most complex problems in medicine, however, checklists are not the only approach to reducing harmful variability. One example is the approach presented in our piece by Mayer et al. on creating a standardized approach to assessing ICU patients in the hope of heading-off variability, and then working to reduce the potential harms before they emerge. Mayer et al. advocate a standardized preventive ethics approach that holds much promise.

Next, the article by Moore, a deep dive into the implementation of restrictive visitation policies at the outset of the COVID-19 pandemic, is an elegant study in the miseries wrought by variability of policy across healthcare institutions and within institutions as policies adapted. Acknowledging that these policies were largely drafted by well-meaning and pandemic-beleaguered administrators, their variabilities nevertheless created harms for patients and families without any assurance that they really improved infection control.

Within the frame of variability, the case analysis by Salupo et al. seems so *sui generis* as not to have anything to do with variability at all. But here too, the specter of variability emerges. From my reading of the hypothetical, the authors threw into a case involving a common problem (i.e., when questionably capacitated patients want to go home to seemingly intolerable environments that could result in certain death) the seemingly bizarre sidebar of a court-appointed guardian who didn't believe the patient required a guardian, and thus

threw the team into turmoil. Variability also exists across all of us in the degree to which we either lean toward the protective side or the autonomy side when concerned over decisional capacity.

Finally, related to our case about the Disability Paradox, in a not-so-obvious way, this analysis shines a light on the variability between clinical prediction and patient outcomes. Here, although somewhat indirectly, variability between prediction and reality urges us all to accept that prediction of patient outcomes can be a perilous undertaking; one that should be approached with the humility it deserves.

Rounding out JoHE's contents with the article by Perry on autonomy and the case on communication, both bring fresh insights. Perry's thorough review of and response to today's major critiques of the concept of autonomy, and reading her analyses of why these critiques don't really hold up is like listening to a Beethoven symphony — once you have heard one, your ability to hear all other symphonies is unalterably deepened. As to the communications piece, if this isn't a universal experience of each of our readers who practice clinical ethics consultation, I don't know what is.

We hope you find the 8.3 issue as interesting to read as we did while producing it. And please, we want to hear from you, so do write us with your thoughts. In the meantime, stay safe.



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FEATURES

Universal Ethics Evaluation of ICU Patients: A Model

Patricia A. Mayer, MD, MS, HEC-C; Duncan C. McElfresh, PhD and Katherine Bracamontes, BS

Abstract

Background: Clinical ethics consultations are typically provided on a reactive basis and in response to ethical dilemmas or crises. Proactive clinical ethics might be preventative; however proactive ethics has primarily been demonstrated in academic settings with specific patient groups. We propose an approach in which every patient in the intensive care unit is screened for specific, actionable ethics-related criteria. **Methods:** Our methods were developed during a one-year pilot in which a clinical ethicist was embedded in an ICU. The ethicist evaluated as many patients as possible with no explicit selection criteria; three hundred and seventy-three patients were evaluated (39% of all admitted patients). The ethicist used four ethics-related criteria to assess patients for potentially problematic ethical issues: (a) Code Status, (b) presence/absence of Medical Power of Attorney or correctly identified Surrogate Decision Maker (c) presence/absence of Goals/Plan of Care consistent with patient wishes, and (d) presence/absence of Conflict. The time spent by the ethicist was recorded for each patient, and financial impact was evaluated separately by the institution. We retrospectively analyze these ethics-related criteria in conjunction with patient outcomes for the hospitalization. **Results and Conclusions:** Over two-thirds of the patients had problematic findings on initial evaluation in at least one of the four ethics criteria; 20% had no Code Status selected, 57% had no MPOA or surrogate, 49% had no clear Goals/Plan of Care and 25% had Conflict present. Of the 80% of patients with an initial Code Status, 25% were changed during the hospitalization. 22 % of the patients screened needed no ethics intervention/support, 47% received intermediate support, and 31% required extensive ethics support. Each of the four ethics-related criteria was associated with a greater need for ethics support, and each can be quickly assessed. We hope that our methods will inspire other innovations in clinical ethics consultation services.

Introduction

Clinical Ethics Consultations (CEC) are commonly requested in intensive care unit (ICU) settings. In the United States approximately 81% of all hospitals offer a mechanism for bedside CEC services including nearly all hospitals with at least 400 beds, though hours of availability are highly variable.¹⁻⁴ Clinical ethicists are typically called in response to specific requests, and often after significant conflict is already present. Thus ethics commonly serves as crisis control, less often as crisis prevention. In addition, trained ethicists providing CEC are a scarce resource since the need for clinical ethics is greater than the supply.⁵ Further complicating CEC is the wide variation in the skills, training, and availability of those providing the services.¹⁻⁴ Hospitals are required by the Joint Commission to establish a process for “resolving ethical dilemmas,”⁶ and hospitals that do not offer CEC meet this requirement with ethics committees. Engaging with these committees can be cumbersome for clinicians, and committee involvement is often too slow to meet the urgency required in an ICU.⁷ Effective CEC can benefit patients, surrogates/families, treating teams and institutions. There is evidence that CEC reduces length of hospital stay,⁸⁻¹⁰ reduces overall healthcare costs,¹¹⁻¹² decreases moral distress among hospital staff,¹³ and leads to patient outcomes more closely aligned with

patient goals.¹⁴ Au et al.¹⁵ offer a comprehensive review of outcome measures used in CEC.

Despite clear benefits to patients and providers, dedicated CEC is underutilized. A recent survey of US hospitals found that while 86% of surveyed hospitals report availability of an ethics consultation service, most hospitals report performing only one or two CECs annually (with three as the median number of annual consultations per institution).²

Recognizing the limitations of traditional CEC and institutional ethics committees, we propose another mode of clinical ethics that is both routine and proactive. Specifically, we propose a rapid universal clinical ethics screening for all patients admitted to the ICU. We developed a version of this screening as part of a pilot in which a clinical ethicist was embedded, working full time in an ICU for a full calendar year, and who evaluated as many patients as possible. The ethicist developed a screening to rapidly assess potential ethics issues for each patient, drawing inspiration from earlier studies of proactive CEC¹⁶ and her own extensive experience in clinical ethics consultations. This screening is based on four ethics-related criteria, each of which are known reasons for clinical ethics consultations. We find that these factors are associated with both the amount of ethics re-

sources required and clinical outcome. To our knowledge, this use of clinical ethics resources is unprecedented; and to our knowledge, our method for rapidly and universally evaluating patients for ethics-related criteria is novel. We hope that our methods will inspire other innovative uses of proactive clinical ethics.

Background: The Pilot Program

This paper is based on a pilot program conducted in one facility of a multi-state hospital system to investigate the value of a dedicated clinical ethicist. We recognize having a clinical ethicist available full time in a single ICU is novel; this pilot was funded by an internal grant that supported this concept. Prior to this pilot there were no dedicated clinical ethicists in the hospital system, and all formal ethics consultations were conducted through facility-based committees; the committee at our host facility reported 2-4 consults per year. We briefly report the financial impact of the pilot in the Results section. The financial results are interesting but not novel; several studies have reported that clinical ethics can decrease cost of care, length of stay, and mortality, among other benefits. We do not present financial results in detail since they were not conducted by the authors but rather by the host institution's financial office.

Institutional Buy-In

Establishing and maintaining institutional buy-in is essential to establish a new protocol in any hospital unit, particularly in an ICU. Intensivists in our location actively requested an embedded ethicist; this proved key to the success of the project. Over several months prior to beginning the pilot, the ethicist met with multiple stakeholders to discuss and clarify intentions of the pilot and to answer questions about the role, responsibilities, and limits of the ethicist. The ethicist was explicit that she would be working in conjunction with the treating teams - not independently. During the pilot, the clinical ethicist attended daily multidisciplinary rounds as part of the ICU team and fostered close ties with other services, particularly oncology, hospital medicine, and palliative medicine. To maintain buy-in, the ethicist was in constant communication with the intensivists throughout the pilot including discussing ethics involvement with them and other treating teams before providing services. However, consistent with traditional CEC practice, the ethicist conducted consultations by request, available to all. We did not encounter situations in which one party wanted a consultation and another was opposed. In addition, clinicians requested and received specific ethics assistance, such as interpreting advance directives, determining the correct surrogate decision-maker, and conducting family meetings. This communication and cooperation with treating services was essential to the acceptance of a routine ethics presence. There were no complaints from ICU staff, treating teams, pa-

tients, or hospital administration about the pilot; on the contrary the embedded ethicist was welcomed.

MATERIALS AND METHODS

The pilot took place from January 7th, 2019 through December 29th, 2019. During this period, an experienced and trained clinical ethicist evaluated as many patients as possible admitted to the twelve bed ICU in a community hospital associated with a leading cancer center. During the pilot the ethicist was primarily present in the ICU during weekday daytime hours. When in the ICU, the ethicist performed chart reviews and then saw all patients who were currently admitted to the ICU. No attempt was made to prioritize patients. She completed MPOAs (a total of 150) when patients had capacity and met with treating teams, nurses, families and surrogates when they were available and when appropriate. The ethicist did not evaluate any patients whose ICU admission did not overlap with her working hours; since the host ICU was small, it proved feasible for the ethicist to visit all patients whose admissions overlapped with her working hours. All patient interactions were in-person. Patients or their surrogate decision-makers were requested but not required to interact with the ethicist; none refused.

All consultations were guided by the ethicist's clinical training and experience. There is no standardized script for discussing clinical ethics topics---including the criteria listed in the following section. This leads to high variability in the content and quality of ethics consultations overall, which is a known problem. And while we do not endeavor to resolve this issue here, we appreciate the importance of ongoing work to standardize clinical ethics consultations.¹⁷⁻¹⁸

The ethicist collected four ethics-related criteria for each patient, described in detail below. In addition, standard demographic information and the clinical outcome of the hospitalization were collected and recorded. The sponsoring institution's finance office independently collated and analyzed financial data.

Ethics-Related Criteria

To assess the general need for clinical ethics, the ethicist collected four ethics-related criteria for each patient: Code Status, identification of a correct surrogate Decision Maker ("DM"), patient Goals or Plan of Care ("Goals"), and presence of Conflict. These criteria were chosen based on the ethicist's professional experience, and their relevance to clinical ethics is well-established in the literature.¹⁹⁻²¹ Details of each criterion are given below. All criteria were recorded prior to ethics involvement to assess potential sources of clinical ethics issues. Code Status, DM, and Goals were also recorded after involvement.

Code Status was recorded from each patient's electronic medical record (EMR) both before and after

*When a Code Status is selected in our EMR, 4 options are offered in the drop-down menu: FC, DNR/DNI, CPR without Intubation, and Intubation without CPR. The single patient with a Code Status of "CPR without Intubation" was classified as FC, and the patients for whom "Intubation without CPR" was selected (7 prior to ethics, 17 after) were included in the DNR/DNI group because the intubations were either elective (not part of CPR) or occurred prior to the Code Status change.

ethics involvement and analyzed as one of three options: (a) “Full Code” (FC) - full cardiopulmonary resuscitation (CPR) to be initiated for a cardiopulmonary arrest, (b) “Do not resuscitate” (in our EMR, DNR is represented as “DNR/DNI”) - resuscitative measures will not be implemented for a cardiopulmonary arrest, or (c) “No order entered” (No Status) - which defaults to FC in an arrest. The ethicist and clinicians discussed Code Status with all patients, whether or not a status had already been entered in the EMR. We also recorded each patient’s final Code Status (after ethics involvement).

DM was recorded after review of the EMR as “Yes” or “No.” “Yes” indicated DM was correctly identified in the EMR as either a formal Medical Power of Attorney or statutory surrogate. Patients without a DM were assisted in completing a Medical Power of Attorney document (if they had capacity); otherwise, the correct statutory surrogate was identified and recorded in the EMR. Since many ICU patients lack or lose capacity, establishing the correct DM was a particular focus of ethics efforts. The ethicist found that correct identification of a DM helped decrease ethical dilemmas, particularly in the context of significant family conflict or disagreement about patient preferences. For example, the ethicist encountered several cases where statutory surrogates were in conflict with one another. In such cases, it was invaluable to have a completed MPOA prior to patients losing capacity because our state requires a majority of statutory surrogates to agree to a plan of care. This is not a hypothetical dilemma; we experienced several cases of both verbal and physical altercations between adult children of patients

Goals were identified from the EMR and initial patient meeting. Goals were considered complete (recorded as “Yes”) when clear plans and treatment goals for the acute problem as well as pertinent associated problems were present and consistent with patient goals, otherwise Goals were incomplete (recorded as “No”). Determining a patient’s Goals is challenging in general, and some judgment was required in scoring this variable. For example, a patient with treatment resistant metastatic cancer admitted with sepsis would be recorded as having complete Goals if both the cancer and sepsis were addressed. Unless Goals were obviously present during screening, this indicator was recorded as “No.” For patients with incomplete Goals, the ethicist helped identify and record them.

Conflict was identified by observation and by direct queries of parties involved—including health care workers, patients, DMs, and family members. Conflict was recorded as “Yes” if observed or reported by any party, and “No” otherwise. While this definition of Conflict is subjective, we found that involved parties were unequivocal in reporting the presence or absence of Conflict. In other settings it may be more difficult to determine the presence of Conflict than in this pilot, and we describe limitations of this approach in the Discussion section.

We consider each of the four ethics-related criteria

described above as risk factors for clinical ethics dilemmas. Clinical ethics dilemmas are more likely to arise with patients who (a) do not have a Code Status or have an incorrect status, (b) do not have Goals, (c) do not have a correctly identified DM or (d) have Conflict present during their hospitalization.

Level of Ethics Involvement

While patient indicators and outcomes can help us understand the impact of CEC, it is also essential to understand the resource intensity of effective CEC; this is especially important when clinical ethics resources are scarce, as in our pilot. One measure of resource intensity is the amount of time spent by the ethicist on each patient. The ethicist recorded the level of ethics involvement required for each patient on a three-tier system: minimal (usually an hour or less), intermediate (1-3 hours with needed tasks usually accomplished in a single day), and extensive (over 3 hours). Some extensive cases involved many days, and occasionally weeks, of involvement.

RESULTS

All statements of independence in this section use a chi-square test unless specified otherwise.

The ethicist evaluated 373 patients, representing 39% of the 953 total patients admitted to the ICU during the pilot year. **Table 1** shows basic demographics for patients in our pilot. There were slightly more men than women in our cohort, about three quarters of the patients were over age 50, and just over a third were age 70 or above. This is consistent with the population of our host institution, which specializes in cancer.

Table 1: Summary patient demographics.

Demographic Group	Number of patients (%)
Gender	
Female	170 (46%)
Male	203 (54%)
Age	
<18	0
18-29	27 (7%)
30-39	29 (8%)
40-49	32 (9%)
50-59	58 (16%)
60-69	88 (24%)
70-79	97 (26%)
>80	42 (11%)
Total	373

Table 2 shows the number of patients with each ethics-related criteria prior to and after ethics involvement and the overall prevalence of ethics-related criteria. Over two-thirds of all patients had at least one of these criteria identified during their initial screening. The most common factors were lack of a DM (57%) and incomplete Goals (49%).

Table 2: Prevalence of ethics-related risk factors, before and after ethics involvement*

Ethics-Related Risk Factors	Number (Percentage) of Patients Before and After Ethics	
	Factor 1: Absent Code Status	75 (20%)
Factor 2: No DM Identified	212 (57%)	4 (1%)
Factor 3: No Goals	182 (49%)	6 (2%)
Factor 4: Conflict	95 (25%)	N/A
Overall Prevalence of Risk Factors		
Patients with no risk factors	100 (27%)	
Patients with one risk factor	171 (46%)	
Patients with two risk factors	95 (25%)	
Patients with three risk factors	7 (2%)	
Patients with four risk factors	0	

*The first four rows show the prevalence of each risk factor before and after ethics, and the bottom five rows show the number of patients with one or more risk factors present initially.

Many patients had a change of Code Status after discussions with the ethicist, the intensivist, the specialty treating teams or some combination of the three. The ethicist often, but not always, led these discussions with patients and families after coordinating with others. **Table 3** illustrates the number of patients with each Code Status before and after ethics involvement as well as the hospitalization outcome for each group. Of patients who had No Status prior to ethics involvement, most were changed to FC. Of the 260 patients who were originally FC, 76 (29%) changed to DNR. No patients with an initial DNR changed to FC.

Table 3: Patient outcomes by pre- and post-ethics Code Status.

Pre-Ethics Code Status ^a	Post-Ethics Code Status ^a	Total Number of Patients	Patient Outcomes	
			Expired ^b	Survived to Discharge ^c
No Status	FC	57	6	51
FC	FC	184	11 ^d	173
DNR	FC	0	N/A	N/A
No Status	DNR	18	12	6
FC	DNR	76	60	16
DNR	DNR	38	27	11
Total		373	116	257

a: Two additional code status descriptions in the local EMR were combined with the above as the numbers were insignificant. “Intubation without CPR” was combined with DNR and “CPR without intubation” was combined with FC.

b: “Expired” includes those who expired in the hospital or were actively dying when discharged to hospice.

c: “Survived” includes all discharges to home without hospice and transfers to non-hospice facilities (skilled nursing, rehab, higher level of care).

d: Includes 5 who transitioned to hospice with DNR after ethics involvement.

The proportion of patients with DNR and FC is significantly different pre- and post-ethics ($p < .001$). Prior to ethics involvement, 87% of patients with a recorded status were FC; after ethics 65% of patients were FC. We note that many patients whose Code Status was changed to DNR (from FC or No Status) expired during their hospital admission. Overall, 12 patients who changed from No Status to DNR expired, and 60 patients who changed from FC to DNR expired. We believe without ethics involvement or availability these 72 patients likely would have received unwanted CPR at end of life.

There is also a significant correlation between final Code Status and survival to discharge. Of the 241 patients with FC as their final status, 224 (93%) survived to discharge; of the 132 patients whose final Code Status was DNR, only 33 (25%) survived to discharge.

Level of Ethics Involvement

Table 4 shows the level of ethics involvement for all patients: 79 (22%) had minimal involvement, 172 (48%) had intermediate involvement, and 108 (30%) had extensive involvement. The following analysis explores associations between the level of involvement and the four ethics-related criteria.

Table 4: Level of ethics involvement by each ethics-related risk factor collected during initial meeting

Ethics-Related Risk Factors	Level of Ethics Involvement			Total Number of Patients
	Minimal	Intermediate	Extensive	
Conflict Identified				
Yes	0 (0%)	29 (31%)	66 (69%)	95
No	76 (29%)	141 (54%)	42 (16%)	259
Goals/POC				
Yes	57 (32%)	98 (55%)	24 (13%)	179
No	19 (11%)	72 (41%)	84 (48%)	175
DM				
Yes	57 (38%)	39 (26%)	54 (36%)	150
No	19 (9%)	131 (64%)	54 (26%)	204
Overall	76 (21%)	170 (48%)	108 (31%)	354^a

a: Only patients with all indicators recorded are included in the analysis (N=354)

We use ordinal logistic regression to infer “Level of Ethics Involvement” as a dependent variable (coded as 1 = Minimal, 2 = Intermediate, and 3 = Extensive), and four binary dependent variables: presence of Conflict (“Conflict”), absence of a DM (“No DM”), absence of Goals (“No Goals”), and absence of a Code Status in the EMR (“No Status”); we also include patient sex and age (binned by decade) as controls. The regression coefficients are reported in **Table 5 (next page)**.

Three of the four criteria were associated with greater levels of ethics involvement. Patients with Conflict were ten times more likely to have greater ethics involvement than those without; patients with No Goals and with No DM were between two and three times respectively more likely to have greater ethics involvement. Older patients

were also slightly more likely to have greater levels of ethics involvement. Absent Code Status was not significantly related to the level of ethics involvement, though this lack of significance may be due to strong correlations between indicators.

Table 5: Ordinal logistic regression results for ethics-related indicator (independent variables) and level of ethics involvement (dependent variable).*

Independent Variable	Odds Ratio +/- std. error	z	P> z
Conflict	9.9 +/- 3.0	7.8	<.001
No Goals	2.8 +/- 0.7	4.2	<.001
No DM	2.2 +/- 0.5	3.4	.001
Absent Code Status	0.9 +/- 0.2	-0.4	.713
Age group	1.1 +/- 0.1	2.1	.033
Sex (female)	1.0 +/- 0.2	-0.2	.815

* Significant variables (p<.05) are shown in bold; control variables are shown in the bottom two rows.

Using a Pearson correlation test, both Conflict (r=0.5, p<.001) and Goals (r=0.4, p<.001) are positively correlated with the level of ethics involvement. We did not find a significant correlation between ethics involvement and No DM or Absent Code Status, though this may be due to small sample size or correlations between independent variables. We believe that both indicators are still important as they are intimately related to the development of Goals and are significant sources of Conflict.¹⁶⁻¹⁷

Both Conflict and lack of Goals are associated with the level of ethics involvement, and we recognize these indicators are also positively correlated with each other (r=0.4, p<.001). That is, patients with Conflict are also likely to lack Goals (and vice versa). There are several caveats to this analysis, which we describe in the Discussion section.

Financial Impact

The sponsoring institution separately completed an analysis of financial metrics related to the pilot and found a lower average length of stay with lower average hospital costs, no change in ICU mortality and substantial savings to the campus. The comparison group used by the finance office consisted of matched controls and DRGs from the prior calendar year (2018) when there was no CEC presence in the facility. The positive financial impact contributed to the retention of CEC locally and a decision by leadership to expand across the larger system.

The primary focus of this study was on clinical effects and outcomes, not on financial impact. We include this brief report of financial impact here since it was important to our host institution and will likely be important to other programs. There is controversy over whether and how finances should factor into clinical ethics.^{11, 22-26} We leave it to others continue this discussion.

Discussion

Since clinical ethics is typically a reactive service, it is extremely difficult for healthcare providers to estimate the need for ethics support.²⁷ During a one-year pilot we investigated the impact of an embedded clinical ethicist tasked with evaluating as many patients as possible. As a result, the ethicist developed methods for rapidly screening all patients admitted to the ICU for potential ethics issues and conducted full consultations when requested. Unlike existing models of clinical ethics, our use of an embedded ethicist was both routine and proactive. Data collected during these screenings, paired with requested ethics support, helps us quantify the need for clinical ethics in our institution.

Over two-thirds of patients in our pilot had at least one problematic ethics-related criteria (Table 2), yet most patients required only "minimal" or "intermediate" ethics involvement (Table 4). However, 31% of ICU patients required "extensive" ethics involvement including a full CEC. This is a far greater incidence of ethics issues than reported by CEC services in other hospitals—most of which report 1 or 2 CECs per year.² We suspect that the high number of clinical ethics dilemmas reported in our results is not unique to our ICU. We suspect many clinical ethics issues in other settings are undiscovered and/or unresolved---especially when ethics support is not routine or is less readily available. On the other hand, it is important to avoid overutilization of ethics services, especially when supply is limited.²⁷ As a solution to this dilemma we propose a clinical ethics screening (CES) process to assess

patient need for ethics support.

Introducing Routine CES

Based on our findings, we believe that routine CES can help identify patients who are either likely or unlikely to need clinical ethics support during their hospitalization. Such screening could help direct limited ethics resources to high-needs patients; intervening early in such situations could prevent or mitigate ethics dilemmas, including forgoing unwanted treatments or therapies particularly at end of life. Most importantly, screening could enable clinical ethics to shift from crisis management to crisis prevention.

An initial version of CES could assess the four ethics-related factors collected during the pilot: Code Status, DM, Goals, and Conflict. Each of these indicators were associated with a patient's need for ethics support and each can be quickly assessed. A simple version of this screening could be conducted by a trained staff member with ethics to be formally consulted if needed. We are developing a formal CES screening tool in ongoing work.

Limitations

Our methods and results are based on a single-site pilot, and we do not expect them to generalize to all settings. There are several important caveats to our methods and results. Institution size & culture: The pilot program relied on a strong collaboration between the ethicist and ICU health care workers, which may not be the norm. The host ICU is small, there was no turnover among the three intensivists during the pilot, and ICU health care workers felt free to report conflicts, making Conflict identification simple. Data collection: All data reported in **Tables 1, 2, 3, and 4** were collected by the ethicist. Since some of these data are subjective it is possible that personal bias influenced these results. Before a clinical ethics screening tool is deployed, it should be validated; this is a focus of our ongoing work. Data analysis: The four ethics-related criteria reported are highly correlated with each other, so we cannot determine the predictive power of each factor independently. Patient population: Our host hospital is affiliated with a leading cancer center, and the diagnoses of patients admitted to our ICU reflect this fact. So the clinical ethics screening process developed here may not translate to other patient populations, such as those seen in a predominantly pediatric hospital, for instance. Clinical ethicist: A single ethicist performed all the clinical ethics duties in this pilot.

CONCLUSIONS

During a year-long pilot a clinical ethicist endeavored to evaluate as many patients as possible admitted to a twelve-bed ICU without any prioritization or pre-screening. As a result, we developed a routine Clinical Ethics Screening (CES) based on four ethics-related criteria we consider risk factors for ethical dilemmas. CES can direct targeted use of scarce ethics resources;

in this pilot approximately one third of all patients evaluated had a full CEC.

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Approval

This program and data collection practices were approved by the Banner Institutional Review Board (#47-19-0021) with expedited approval and no requirement for informed consent or HIPAA authorization.

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At What Cost? Analyzing Hospital Visitation Restrictions in a Pandemic Using a Public Health Ethics Framework

Bryanna Moore, PhD

Abstract

Despite all that has been written and said about the COVID-19 pandemic, there is a surprising dearth of ethical analyses of the hospital visitation restrictions that were introduced in response to the COVID-19 virus. These visitation restrictions have been a curious mix of gospel and controversy. This paper briefly sketches five relevant public health values: effectiveness, proportionality, necessity, least infringement and public justification. It then analyzes whether the COVID-19 visitation restrictions served those values. Although the visitation policies may have served some public health values, they appear to have failed others, casting doubt on whether they are ethically supported according to a public health ethics framework.

Introduction

'visit' [verb]: "go to see (someone or something) for a specific purpose"; "(chiefly in biblical use) (of God) come to (a person or place) to bring comfort or salvation."

'visitation' [noun]: "a gathering with the family of a deceased person before the funeral"; "the appearance of a divine or supernatural being"; "a disaster or difficulty regarded as a divine punishment: a visitation of the plague."¹

Despite all that has been written and said about the Covid-19 pandemic, there is a surprising dearth of ethical analyses of the hospital visitation restrictions that were introduced in response to the COVID-19 virus—once new, now familiar controls over who can enter the hospital, at what times, how long for, and in what proximity any visitors can be to patients. Visitation restrictions remain in place in most hospitals, including the one where I work as a clinical ethicist. They have been a curious mix of gospel and controversy. On the one hand, such constraints have seemed unquestionably necessary—how could we not implement such strict controls in the face of a dangerous, highly transmissible threat? On the other hand, the restrictions have been a source of tremendous

psychological and moral distress.² They were in tension with traditional bedside ethics. The assumption that prioritizing the safety of our communities required sacrifices to patient and family-centered care was widely accepted.³ The question, then, is whether the visitation policies have lived up to public health ethics values. In this paper, five relevant public health values are briefly outlined. The COVID-19 visitation restrictions are then analyzed against those values. While the visitation restrictions may have served some public health values, they have failed others, casting doubt on whether they are ethically supported according to a public health ethics framework.

Public Health Ethics and the COVID-19 Visitation Restrictions

Public health scholars and ethicists have proposed several public health ethics frameworks to guide public health interventions.^{4,5} This paper evaluates the visitation policies against five consistently cited public health values: effectiveness, proportionality, necessity, least infringement, and public justification.⁶ This is not an exhaustive list of public health values, nor is this approach the only way to go about ethically assessing the COVID-19 visitation restrictions. And, of course, these values may be misguided values. However, assuming there is general

agreement that something like these values should serve as an ethical guide for public health interventions, their application to the visitation policies is fitting.⁷ Due to limited space, this analysis will be brief and incomplete. It is my hope that this paper will prompt a more focused conversation about the ethical permissibility of such measures. ‘Visitation restrictions’ or ‘visitation policies’ will be used to refer to any policy that dictates who is allowed to enter a hospital to visit a patient and under which circumstances.

1. Effectiveness: *infringing one or more general considerations should be likely to protect public health and bring about the stated goal(s) of the intervention.*

The aim of the visitation restrictions was, presumably, to prevent those within the hospital, and possibly the broader community, from contracting COVID-19 or, at the very least, minimizing the risk of people contracting it. It is difficult to assess whether the visitation restrictions were effective at accomplishing this goal, because it is difficult to disentangle their effect from the effects other infection control and monitoring measures that were in place in hospitals. Temperature screening, declaring symptoms, and mask and hand hygiene mandates were required for all entry to the hospital, not just entry by patients’ visitors. This was during the same phase of the pandemic in which anyone who could was staying home, working remotely, avoiding travel, self-isolating or quarantining when necessary, and wearing masks in shared spaces. Even if we grant that, at least in the early months of the pandemic, the restrictions helped save lives and prevent many cases of sickness, the lack of coordination between infection control measures within hospitals and other community spaces calls the effectiveness of the visitation restrictions themselves into question.

Additionally, exceptions to the restrictions have been made throughout the pandemic for patients who are minors, identify as having a certain disability or impairment, are pregnant, have certain psychiatric conditions, or other “special, compassionate or extenuating circumstances”. Almost all visitation policies have operationalized terms such as ‘imminently dying’, ‘actively dying’, dying or at the “end of life” to create a space for further exceptions. Different individuals and institutions drew boundaries in different places. Sometimes, a patient’s condition determined whether they were at the “end of life”; at other times, a patient, or surrogate’s decisions about their goals of care has determined this. Terms such as “end of life” are difficult to define and often a matter of clinical discretion, despite there being no consensus on such definitions in the medical community.^{8,9} There was also more than usual malleability surrounding what counted as “dying” or irreversible in the early months of the pandemic, given our nascent understanding of the disease.

Similarly, there was widespread variation across hospitals’ policies—even hospitals in the same part of the same city, responding to what was presumably the

same risk of community spread.¹⁰ Given that (1) exceptions to stringent restrictions could be made in a way that seemed to effectively managed the risk of transmission, especially in that first year, pre-vaccine rollout, and (2) visitation policies ranged from strict to lenient, and inconsistently operationalized vague terms, creating widespread variation in their uptake, it is not clear that it was the visitation restrictions that did the work of minimizing spread of the virus, rather than the vigilant use of personal protective equipment (PPE) and physical distancing within the hospital walls.

2. Proportionality: *the expected public health benefits associated with an intervention should outweigh the harms associated with infringing other moral considerations, such as individual rights.*

The difficulty associated with accounting for the benefits and harms associated with the restrictions means that assessing whether they were a proportionate response to the risk of contracting COVID-19 is also difficult, especially without considering the perspectives of all those affected by them. In the United States alone, there have been one million reported deaths due to the virus.¹² The pandemic has disproportionately affected Black and Hispanic communities.^{13,14} The restrictions have prevented care and grieving and increased the burden on already over-burdened healthcare workers.^{15,16} Visitation helps care teams navigate communicating with patients and facilitates decision making, as it exposes families to experiential knowledge of patient’s condition.^{17,18} These important benefits were lost when the restrictions were implemented.^{19,20,21} Some have noted the correlation between being isolated and experiencing poorer health outcomes for patients.²² For some, workarounds such as video visits were viewed as worse than having no contact with their loved ones.²³ In other words, even if the visitation restrictions did carry the benefit of preventing spread of the virus within the hospital’s walls, the visitation restrictions also carried significant costs for all who were constrained by them, costs for which we failed to account.²⁴ When the costs associated with visitation restrictions have been so disproportionately experienced by certain communities, any claims that the restrictions were a proportionate response ought to be treated as suspicious.^{25,26}

3. Necessity: *there should be no other options that can be taken to achieve the public health goal in question. For the purposes of this paper, this principle will be taken to include the idea that the intervention should be a last resort.*

Whether the restrictions were necessary remains a somewhat open, empirical question. The alternative was adopting less stringent measures and risking more cases and more deaths, and that seemed to be a counterfactual on which no one wanted to gamble. The necessity of strict visitation restrictions has been called into

question before.²⁷ At times, the visitation policies have not reflected our evolving understanding of the virus.²⁸ Even if we assume that the restrictions were necessary in the early months of the pandemic, before PPE needs were understood and addressed and vaccines became available, it's not clear that tight controls over who was allowed to visit patients remained necessary in order to prevent or minimize the risk of contracting COVID-19.²⁹ In other words, this goal might, arguably, have been achieved by other means such as diligent masking and use of PPE, the continued use of temperature and symptom screening at entrances, the provision of rapid testing, and coordinated case tracking. Most hospitals have relaxed their visitation policies over time. The pandemic has continued much longer than anticipated, the public's willingness to adhere to tight constraints has waned, and our sense of what's "necessary" to meet shared goals has changed. Certainly, there are logistical and political barriers to implementing alternatives to the strict visitation restrictions that most hospitals adopted. The point is simply that there were alternatives that may not have been adequately considered. With some coordinated effort, it may have been possible to implement those alternatives. This casts doubt on whether keeping families apart at critical times such as births and deaths was the only way of effectively managing the risk of contracting COVID-19.

4. Least Infringement: *any infringement upon general moral considerations should be minimized and as non-intrusive as possible.*³⁰

Can the impact of the visitation policies be framed in terms of intrusive infringements? Are people morally entitled to see their loved ones when they are sick? Was this moral entitlement infringed by hospitals vis-à-vis the policies? If so, were there other, less intrusive ways of doing so? Even before COVID-19, there were some limits on who could be in the hospital and under what circumstances. Yet most of us subscribe to the social expectation that families can be together during big life moments like births and deaths, at the very least. It is fair to hazard a guess that many families who were separated during the pandemic probably feel that their rights were violated by hospitals and that there may have been other, less "intrusive" ways of going about things, assuming such violations were necessary. This is another area where a more honest conversation about any alternatives needed to happen earlier and throughout the COVID-19 experience to date. It also highlights the need for additional data on the experiences of those impacted by the hospital visitation restrictions, especially those for whom other moral considerations were disproportionately infringed by the restrictions, such as persons with disabilities. That is, the effect of the restrictions was significant and extremely intrusive for some individuals and groups, but not others.

5. Public Justification: *the rights infringement should be explained and justified, i.e., the processes by which*

decisions about who could enter the hospital should be made publicly accessible, known, and open to scrutiny. Some might frame this value in terms of openness and transparency.

Anecdotally, some hospitals provided information about the visitation policies on their websites or flyers that were hung in the hospital. The messaging from hospital administration has largely been "COVID19 is a threat and we have to keep everyone safe by limiting visitors". At my hospital, we have received weekly or monthly updates from Incident Command regarding any changes in policies since the start of the pandemic, but those are internal updates, not public ones, and they are certainly not justifications in the sense intended by this value—a clear explanation for how individual and collective rights and interests are being understood, and a reasoned argument for how these individual and collective rights are being weighed, that connects what is known about the virus to the visitation restrictions that are currently in place. As such, it is fair to say that most hospital visitation restrictions probably did not serve this value. Public justification helps to create accountability. Those designing visitation policies and making decisions about exceptions should be answerable for their choices. The policies should have been reviewed and revised throughout the pandemic, with an ongoing commitment to public justification. Some hospitals did revise their policies over time, responding to developments such as vaccines by relaxing their restrictions or attempting to mirror the advice given by public health organizations.

Conclusion

One might be reluctant to criticize those tasked with developing and implementing the COVID-19 visitation restrictions—these were, for the most part, exhausted, afraid, overwhelmed healthcare workers and administrators who were trying to keep people safe. Yet the hospital visitation restrictions have come at a terrible cost, especially for marginalized communities, who have, and will continue to, disproportionately experience the hardships of the pandemic.^{31,32} Evaluated against a public health ethics framework, it is not clear that the visitation restrictions were ethically supported, especially measured against the values of proportionality and public justification. Hospital policies that lack awareness of and sensitivity towards the disproportionate impact of Covid-19 on certain communities, will struggle to satisfy not only conventional ethical commitments but also public health values.³³

This paper has highlighted significant gaps in our understanding of some aspects of the visitation restrictions, raised questions about the assumptions underpinning them and turned a critical eye on exactly who the "public" has been whose health these restrictions claim to serve. What was intended as a public health intervention may have quickly become bad public health ethics. The narrative that there had to be a trade-off between individual rights and public health

measures went largely unquestioned.³⁴ Ethical reflexivity was lost. The language of “protections,” “safety,” “security,” “public health,” and “the common good,” masked important normative assumptions, leaving little room for other values. The important questions of whose safety, and of what kind, went unexamined. Hospitals wielded, as they always have, immense power over how people live and die within their walls.

What does this mean for clinical ethicists? Insofar as clinical ethics is committed to ensuring the implementation of ethically supported policies within healthcare institutions, a public health ethics lens gives clinical ethicists tools to critique and communicate the limits of visitation restrictions. The COVID-19 pandemic has illuminated the need for clinical ethicists—whose education and training has typically focused on bedside ethics and care—to be exposed to public health ethics theory, history, and discourse, if they are to ethically serve their patients.

Of course, it may be misguided to think of the COVID-19 visitation policies as a public health measure. They may be something else entirely and it may be unfair to evaluate them against public health ethics standards. But then, it must be asked, what were they? What have they become? What, ethically, grounds them?

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Autonomy and Clinical Ethics: Don't Throw Autonomy out with the Bathwater

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Abstract

Growing criticism of the role of autonomy in American bioethics is diverse and consistent with calls to address systemic bias and discrimination. The confluence of critiques from different sources warrants the attention of clinical ethics consultants (CEC) since autonomy serves as a guide to clinical ethics practice. Four main critiques are considered below. Lessons from these critiques can improve clinical ethics consultation practice.

Introduction: *The Critiques*

Autonomy, the former darling of American bioethics, has come under scrutiny. It has been called a tool of sexism, racism, ableism, etc. Economic and ethical theorists speak about “nudging” as a means used by the powerful to manipulate people under the guise of free choice.^{1,2} Research on decision making demonstrates the various ways our decisions are influenced or determined by seemingly automatic reactions.³ This evidence calls the very ability to be autonomous into question. Feminist scholars demonstrate the ways autonomy and rationality have been used to sustain male dominance, including both the assumption of male norms and a façade of freedom in a world where the powerful control the options available to those more constrained by social exigencies.⁴ Disability rights advocates also argue that the emphasis on autonomy distorts the value of the differently cognitively abled as lesser and impaired.¹¹⁻¹⁴ Calls to address systemic racism have included a focus on autonomy and free will as promulgating a value system that ignores the many social forces that undermine and undervalue the choices of people of color.^{6,9,15-18}

On the other hand, clinical ethics practice in the United States has developed with an assumption that respect for autonomy matters. It matters enough that it can override the value of continued life. Autonomy can

override professional authority and to a lesser extent, social interests.

Many of the “tools of the trade” in clinical ethics assume the value and importance of autonomy. These include informed consent, advance directives, and surrogacy standards where the patient’s prior statements have greater weight than the surrogate’s judgment of best interests or calls for consideration of the interests of others. Informed consent is a tool to promote autonomy by supporting education, communication, and voluntariness in the patient decision-making process. Previously autonomous people who currently lack decisional capacity have aspects of autonomy preserved through advance directives and a hierarchy of surrogate decision standards which prioritize evidence of the patient’s wishes based on past actions, preferences, and values. Considerations of the impact on others are treated with suspicion, as potentially corrupting influences.

Critiques of autonomy’s role in bioethics include that the emphasis on autonomy is:

- An isolationist denial of the interconnectedness of individuals in society;^{13,19-21}
- A tool of privilege, brandished by those who have the freedom and resources necessary for op-

tions;^{6,9,18}

- A disguise used by the powerful to obscure conditions which disempower vulnerable populations.^{5,6,9,17,22,23}
- A myth that denies social and biological realities;^{3,6,9,18,23,24}

There is truth in this. American clinical ethics has primarily focused on individual patient cases in its practice as if there can be a clear distinction between the care of an individual and the social forces that create the need for and access to care, define the treatment options, influence the choice amongst those options, and impact the outcome. The separation between individual care and social forces is a façade. Options are limited by resources, environment, and support. Health is not distributed fairly or without prejudice. The critics of autonomy are correct.

It is important for clinical ethicists to consider their practice in light of these criticisms. This is especially true given the social movements to root out discrimination and inequity and promote inclusion of disenfranchised groups. The challenges brought by a global pandemic and supply chain problems have further challenged the primacy of individual choice. For example, informed consent discussions are shaped by the clinician's assumptions of what is relevant for the patient, as well as an assumption of the patient's willingness to interact with the clinician to gain any other information he/she needs. If the patient and clinician's perspectives of each other do not overlap, as occurs with discrimination and disenfranchisement, then communication requires more effort to reach understanding. Time and energy for such efforts are further strained by staffing shortages and stress. Autonomy as properly understood can address many concerns raised by critics and guide improvements in clinical ethics practice. But it cannot do this alone.

There is a lot to unpack here. The intention of this article is to spark further thought and discussion. Below is a basic interpretation of autonomy. Then, the criticisms will be analyzed using cases to explain and demonstrate the practical applications to clinical ethics consultation practice. The conclusions are meant to be the beginning of conversations, sparked by what we can learn from the critiques and analysis thereof.

Autonomy

The first and easiest critique to address is the misinterpretation of autonomy in clinical ethics in reductionist terms. Consider a patient who one day begins to refuse all treatment and stops speaking to the clinical care team. Without further discussion, the attending physician withholds treatment "out of respect for autonomy" and tells the patient that she will return when he wants to speak to her. However, respect for autonomy is not as simple as accepting a refusal of treatment.

Autonomy, as I am using it here, is the right and capacity to make one's own decisions, based on one's

own values, and act on those decisions, without undue influence.²⁵⁻³⁰ Respecting autonomy is more than respecting an individual's decision. The assumption is that the decision is well-informed and the result of personal reflection and analysis. In other words, it is the result of the individual's uncoerced choice based on adequate information and reflection. Respect includes supporting the conditions for informed, reflective, and rational decision making.³¹ The decision maker ought to be empowered to make an autonomous choice.

To ensure that autonomy is respected, a clinical ethicist involved in the case above should investigate what led to the sudden change in the patient's decisions, willingness to communicate, and relationship with the care team. This may uncover areas where support for autonomy can be repaired and improved. This will require active listening to those involved and keeping an open mind, which is dependent on communication. Since the patient has stopped speaking, the CEC may need to be creative and rely on other communication strategies, building trust.

This definition of autonomy assumes a connection between capacity and the right. If one never had decisional capacity and never will, one does not have a right to exercise autonomy. Consider a simple autonomous decision, like selecting a favorite lollipop flavor. If a patient never possessed the capacity for choosing a favorite flavor, then there is no identified "patient's favorite flavor." Surrogate decision reflects the surrogate's choice. Patient autonomy is not violated by giving the decision responsibility to someone else. Autonomy is simply not applicable.

Contrast this with an individual who has some autonomous capacity, such as someone who is nonverbal, but conscious and able to follow commands. In this case, the patient's choice of the available flavors should be respected. This may require extra effort to enable the patient to act on that choice such as bringing the lollipops to bedside so that the patient can choose without words.

The level of decisional capacity required depends on the complexity and degree of risk involved in the decision.^{25,28,31} Many clinical ethics consults involve questions of the degree to which an individual is, was, or will be capable of making a deliberative, clinical decision. The answer shapes the decision-making process in a manner that best fits the patient's needs and abilities within the time that the decision needs to be made. Respect for autonomy also requires supporting autonomy. For example, research suggests a correlation between high peripheral glucose levels and improved cognitive performance on working memory, long-term memory, attention and vigilance, reaction times (RTs), verbal fluency, reasoning, and inhibitory control.³² This means that difficult decision making should be coordinated with meals or snacks, if possible. This improves the autonomous ability of everyone involved in the decision-making process.

Support for autonomy requires recognizing the limits of one's knowledge. Autonomy can be under-

mined by assumptions made about an individual's motives, goals, intentions, etc. Communication is key to respect for autonomy. Communication is a social activity. Being a good listener facilitating discourse are important aspects of CEC practice. Thus, respecting autonomy is inherently social. The debate over whether autonomy is socially predicated is interesting and important. But it is beyond the scope of this paper.

But even more important is that how and what we communicate with and understand is shaped by events beyond the current situation. American medicine has been shaped by discrimination, inequity, and exclusion. From robbing African American graveyards for bodies, using slaves and prisoners for research and surgical practice, involuntary sterilization based on race, income, ethnicity, disability, and social status, to the current inequities in morbidity and mortality, many patients do not assume their care team acts from beneficence.^{6,9,17} No matter how undeserved, individuals may be judged based on the actions of others like them. This means that members of the care team need to demonstrate trustworthiness and compassion.

While a clinician may accept the virtue of self-effacement as integral to the role of a clinical care giver, history demonstrates many exceptions to this. The tremendous power inequity in most patient-professional relationships, especially within the hospital environment, can exacerbate the disempowering aspects of illness or injury. Patients factor trustworthiness into care decisions. Empowering the patient/patient surrogate includes providing the information that the patient needs to make a decision. This includes more than the mere medical information. It includes the degree to which the clinician and institution are devoted to supporting the patient's interests and autonomy.

Autonomy as a Tool of Isolation and Disempowerment

Critics argue that autonomy isolates the patient from support systems, ignoring the value of communal and familial approaches to decision making and identity, such as "Ubuntu" (being self through others).³³ This critique is important because CECs realize the value of supported decision making by clinicians and patients. While there are cases where other people can interfere with the patient's decision making, in most cases being alone without the support of loved ones makes a patient more vulnerable. Allowing the patient to decide the degree of involvement of others respects autonomy by supporting the patient's control over who is involved in the decision-making process.

Thankfully, true support for autonomy is not isolationist. Rather, it is a necessary protection for the individual who is enmeshed in a complex social network where not all relationships support and value the individual as a person. The patient mentioned above who is refusing all treatment is reacting to something. The clinical ethics consultant can help by listening to those involved, exploring different routes of communication, improving trust.

This is all guided by a recognition of the imperfection of knowledge and communication. Each person involved in a consult tells a different story. The clinical ethics consultant may be consulted to help solve a problem identified by the clinical team only to discover that the patient sees a different problem. By nurturing communication amongst the patient and the clinical team, the clinical ethicist is supporting the autonomy of each person involved in the case by improving education and understanding about the exigencies of the situation as shaped by those within it. It can be relationship-building if it leads to improved understanding and respect for the other person. By improving understanding of others' perspectives, one promotes respect for those others as autonomous beings even if agreement is not achieved. Without sufficient understanding, the requirements for autonomy are not met. It would be like making a treatment decision without accurate and sufficient information. Reducing autonomy to mere choice is not only inadequate, but anathema to respecting autonomy. Respect for autonomy should not result in isolationism or disempowerment. Quite the opposite, respect for autonomy can improve relationships and empower patients.

A Tool of Privilege

"Choice" assumes the existence of options. Let's assume that a patient has three treatment options for an infected toe: no treatment, amputation of part of the foot, or antibiotics. The patient will likely die without treatment. The patient wants to live and save her toe. She chooses antibiotics, even though she might need a greater amputation if the antibiotic fails. However, the insurance company declares that it will only pay for the amputation, since that is the definitive, least risky, and most cost-effective treatment. The patient cannot afford to pay out of pocket. When asked to sign a consent form for the operation, she turns to the surgeon and says, "In what sense is this my choice?"

In this case, ignoring the particulars ignores the factors that are undermining autonomy. The criticism is not directed at autonomy, but rather the disjunct between theory and reality. It is not simply a critique of unjust conditions in terms of limited access due to her insurance plan, but also the use of autonomy practices like assuring informed consent for a treatment option one did not choose or want. The question of possible injustice is raised not by the mere lack of options. Rather, it is that the options were limited by a third-party decision under conditions that appear coercive. The antibiotic needs to be given quickly to work. There is no time for the appeals process to challenge the coverage decision. Justice issues may run beyond the insurer to include conditions that caused and exacerbated the infection, as well as affected the quality of insurance coverage. But the point is that genuine respect for autonomy requires attention to the conditions that disempower. In this case, the clinical ethicist might work with the clinical care team to identify alternative pay-

ment methods and emergency appeal procedures for the insurance company.

If efforts to expand the patient's choices are insufficient or impossible, it isn't the concept of autonomy that is the problem, but the inability to realize it due to factors beyond one's control in the moment. "In the moment" is key here. Clinical ethics consultation is not confined to the particular case. This case may indicate systemic problems. Solutions may not be available in time for this patient due to the increasing risk of sepsis and the time required to appeal an insurance coverage decision. Any issues raised by the case should not be ignored. Involving this patient in the efforts to address systemic problems identified in her care can address some of the disempowerment she experienced. It demonstrates that the clinical care team recognizes the denial of coverage of the antibiotic option as significant and is trying to address it. Offering the patient a role in the post hoc review returns some control to the individual most affected by the issue through including her voice in improvement efforts.

The inclusion of stakeholders must be done with integrity. This means that stakeholders should be representative of the community for which they speak, be capable and willing to serve in this capacity, and have real power.³⁶ The conditions for participation must also consider the stakeholders. For example, if an ethics committee wants to include community members in discussions of how to respond to insurance refusals of reasonable medical treatment options, when arranging meeting times or inclusion methods, it should consider the availability of all stakeholders, not just the clinical staff. This may require different methods for including diverse stakeholder voices, such as interviews, surveys, virtual meetings, etc.

When we discuss systemic change, we need to evaluate all policies and procedures, especially those accepted as "routine" with an eye to achieving inclusion in practice, not simply appearance. If community members are not attending meetings or speaking up when they do attend, ask them why. The process of evaluating how to improve procedures mirrors the practices that support autonomy (gather information, promote understanding and encourage voluntary decision-making procedures, actively listen and communicate).

Autonomy as a Male Dominated, Individualistic Norm

There is great variety in feminist ethics. But a common theme is the identification and analysis of bias and discrimination embedded within culturally accepted concepts and practices. This includes all who are excluded from the dominant discourse, not just women. For example, care ethics was developed as a response to assumptions within ethical theory that assumed a male-dominated paradigm. Rule-based ethics approaches demand an equality and objectivity that is helpful in dealings with other moral agents who may be virtual strangers. However, it is not very helpful with the ethics of family dynamics. For example, the brother of a

terminally ill patient once told me, "She had her whole life to do as she chose. Not now! This is a family decision, not just hers." So much was in that statement, including the claim that decisions about the patient's care required understanding the family dynamics and the patient's role and responsibilities within her family. The brother was challenging the "rule" that assumed the primacy of the patient's wishes. Her care decisions would reverberate through her connections with her loved ones. He wanted care ethics, not rule ethics.

To refuse to consider this family's approach to end of life decision making is to fail to respect a grief process and set of responsibilities born of their intimate familial connections. It is also applying a western European cultural standpoint, largely developed by white, able-bodied men, to a family that doesn't fit this stereotype. Is that just? Feminist ethics would argue that one should not approach decision making for a family member in the same way one would decide about the allocation of scarce resources amongst strangers. Care decisions for loved ones are expected to be emotional and factor-in actual, lived relationships (not idealized versions). A family consult might begin with family members who disagree about the patient's care. During the family meeting, other issues are raised including grief and loss. The consensus is often an amalgam of considerations of patients' wishes and support for loved ones. For example, treatment withdrawal may be delayed enabling loved ones to be present, say prayers, etc.

Autonomy's role in intimate relationships is complex. The expertise that loved ones bring to ethics consults includes more than information about a patient's values and preferences. The isolationist view of autonomy fails to account for the full identity and existence of the individual existing within and through relationships. Patients value their loved ones and usually consider their interests in decisions.³⁷⁻³⁹ Mary Ann Meeker's study of caregivers and patient decision preferences demonstrated that:

"An overreliance (whether by the care manager or clinician) on patients' autonomy creates a truncated view of the situation, fails to attend to the interdependence within the family, and limits appropriate consideration of the care manager's own needs. And, of course, many dying patients want their families' needs accounted for in decision making and assign high importance to "not being a burden" to their family."³⁹

Yet not all relationships are healthy or supportive. This is where autonomy can serve as a corrective or guide. For example, if the patient above had an advance directive that conflicted with the family's decisions, one ought to hold a family meeting to discuss these discrepancies.

Patients are usually the most vulnerable individual involved in a patient care decision. They are most affected by decisions and disempowered by the situation at hand. Therefore, their interests and autonomy usually

deserve to hold the greatest weight. If the patient has decisional capacity, then the patient can determine how and to what degree the interests of loved ones should influence a decision. When the patient is unable to participate, the CEC should work with the clinical team and those close to the patient to balance evidence of the patient's preference with the interests of the patient and those who care about and for her.

Another concern is the extent to which the treatment decision affects others. John Stuart Mill stated that the right to exercise individual autonomy is limited when it harms others (the Harm Principle).⁴⁰ While the harm principle sounds nice in theory, it provides little help to the spouse of a patient who signs out against medical advice only to require the partner's constant help and care at home. Claims that the partner could refuse sound hollow given the likelihood that the partner will feel pressured emotionally and socially to accept the responsibility of caregiving. Still, it is autonomy concerns for the partner in this case that raise awareness of the need for discussion and negotiation of the expectations and real options prior to leaving the hospital. Voluntariness is a consideration here, not in the artificial sense of complete freedom without consequences, but rather one of degrees including an understanding of potential consequences.

Autonomy considerations can help identify potential issues of abuse, neglect, burnout, or overburden of family caregivers. The clinical ethics consultant can make queries to probe the degree to which the family caregiver is willing and able to accept this responsibility. Similarly, the discussion should include the degree to which a patient is willing to accept this care and the conditions that go with it (such as the partner knowing confidential medical information). Autonomy is not antithetical to care and connection to others. But care decisions are complex and patient autonomy is only one consideration.

Autonomy is a Myth

When researchers speak of autonomy as a myth, they are either saying that the current social reality does not support meaningful choice (which was discussed earlier) or that our actions are all biologically determined. If the latter is true, then our very discussion of free will and autonomy is determined. Furthermore, actions will occur regardless of our erroneous characterization of their cause. If they are determined, we couldn't change them if we wanted to. On the other hand, moral agency is dependent upon the assumption that the action was intentional. If we lack the capacity for intentional action, then it is impossible to translate autonomous choices into action. It can't hurt to assume the possibility of free will, because either it exists, or we have been predetermined to act as if it did.^{33,34} Besides, if our decisions and actions are predetermined, then what is the purpose of ethics consultation?

The argument above relates to bioethics in a practical sense. Our minds are dependent upon neurological

reactions shaped both by individual experience and bodily systems. Knowledge of this can improve CEC practice. After reading about the impact of low glucose on decision making, I started bringing hard candies to family meetings for ethics consults. These meetings typically occur at the end of the day, but prior to dinner. It's not the best time for complex decision making. Studies suggest that sugar might help.^{3,32} It was a simple addition. The sugar gives the brain energy which helps it function more effectively. This is a noncoercive nod to the impact of bodily function on decision making.

Finally, if the claim is that autonomy is a social myth, then again, the critique is not against autonomy conceptually, but rather at a failure to recognize and address factors that unjustifiably diminish it. Charles Mills argued that Descartes was wrong when he reasoned that one could be confident that one existed because one could not doubt that one could think.¹⁵ Mills pointed out that many individuals in the U.S. grow up surrounded by people and institutions that question their ability to reason and even the truth of their own thoughts and experiences. Judith Heumann recounts multiple instances in which someone assumed that her physical disability made her cognitively disabled as well.¹¹ Clinical ethics consultants should be reminded to pay attention to conditions that can undermine or strengthen autonomy and to consider ways to promote equity within the health care system.^{41,42} The American Society of Bioethics and Humanities' Code of Ethics and Responsibilities for Healthcare Ethics Consultants includes the duty to "reduce disparities, discrimination, and inequities when providing consultations."⁴³ Again, the inclusion of stakeholders is important. It can be difficult to see problems that are obvious to individuals who experience the world differently. The more perspectives involved in the process, the better the vision. Inclusion of representative voices happens naturally in clinical ethics consults if one meaningfully includes all relevant to the issue at hand. However, it also refers to promoting diversity on one's ethics committees and evaluating systems and procedures for undue bias with the people who are most intimately aware of this bias.

Conclusion

Autonomy enables individuals to be active agents in the creation of their personal narratives. But autonomy extends beyond the rational decision making of an isolated individual. Respect for autonomy includes an obligation to nurture and empower the autonomous capacity of vulnerable individuals. This includes recognizing and promoting the conditions necessary for autonomy to exist and flourish. When one discovers an obstacle to agency one can begin work to overcome it. In this way, respect for autonomy becomes a tool to uncover bias and promote empowerment. But misused, autonomy can become a tool of disempowerment and oppression. Given the degree to which autonomy is embedded in CEC practice, these criticisms are useful, albeit not sufficient, for a systemic evaluation of con-

cepts and practices that are assumed in clinical ethics practice.

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When the Guardian Relinquishes Decision Making: Limited Capacity in the Legally Incompetent Patient

Nicholas Salupo, DO; Sharon Merryman, DO, MSHI and Jeffrey Kaufhold, MD, HEC-C

Abstract

Prior to this hospitalization, Mrs. L's primary care physician filed a report with the local Adult Protective Services (APS) agency. Upon review of the case, APS determined that Mrs. L had been a victim of elder abuse and neglect. Despite the emergently obtained guardianship order due to what APS reported of the patient's circumstances at home, and regardless of whether or not the patient actually did have the capacity to make a fully autonomous decision to go home, the primary medical team's assessment was that she did not, and they felt duty bound to discharge the patient somewhere they felt was going to constitute a safe discharge. This case presents several ethical considerations that were further complicated by the unusual legal situation of having a court appointed guardian wish to relinquish his court appointment so quickly. First, can a medically frail and socially vulnerable patient, in this case a victim of elder abuse and self-neglect, with at best questionable decisional capacity, make a seemingly unsafe decision to go back into a neglectful environment? Second, does the hospital staff have an obligation to refuse to agree with decisions of a questionably autonomous patient? Finally, who should be ultimately granted decision-making authority if a court-appointed guardian believes his ward has decisional capacity?

PRESENTATION

Mrs. L is a 66-year-old female with a past medical history of depression, lower gastrointestinal bleeding, coronary artery disease, cerebrovascular accident, hypertension, hyperlipidemia, implantable cardioverter defibrillator, severe malnutrition, and scabies presenting from home to a medium-sized community teaching hospital in Colorado for failure to thrive and neglect during the COVID-19 pandemic. She lived at home with her daughter and son-in-law. Her husband was deceased. She had a son whom she declined to involve in her medical care.

Prior to this hospitalization, her primary care physician filed a report with the local Adult Protective Services (APS) agency. Upon review of the case, APS determined that Mrs. L had been a victim of elder abuse and neglect. Through the county probate court, a legal guardian, Mr. K was granted emergency guardianship. Once this guardianship was established, APS agents went to the patient's home in order to bring her to the hospital for a medical evaluation; however, she refused to leave her home. The patient and family refused to cooperate, and APS ultimately required police assistance to remove her from her home. Several dogs were also removed by animal care and control because of the

condition of the residence. Mrs. L was brought to the Colorado Community Hospital and Wellness Center via emergency medical services and was admitted for observation because of failure to thrive.

Mrs. L underwent a thorough evaluation by multiple medical specialists. Pulmonology was consulted for a 1.1 cm pleural based pulmonary nodule in the right upper lobe. The pulmonologist planned for an outpatient positron emission tomography (PET) scan to further evaluate. Gastroenterology was consulted for a 1.4 cm low-attenuation lesion of the right hepatic lobe. The gastroenterologist planned for an outpatient magnetic resonance imaging study to characterize the liver lesion. Oncology was consulted to evaluate both the lung and liver lesions. The oncologist was in agreement with the diagnostic evaluations being pursued by the other specialists. Cardiology was consulted for management of Mrs. L's coronary artery disease and no acute inpatient interventions were indicated. Palliative care was consulted to discuss goals of care, but Mrs. L refused to have a conversation with the palliative care provider. Physical and occupational therapy services recommended that Mrs. L be discharged to a subacute rehabilitation facility to continue receiving therapy services.

However, she refused to be discharged to any facility and demanded to return home with her family.

Concerning the patient's capacity assessment by psychiatry, they found Mrs. L to be cooperative with a stable mood, normal affect, and without hallucinations, delusions, or preoccupations. She denied suicidal or homicidal ideations. She displayed a logical thought process with fair insight and her judgment was intact. Her recent and remote history was intact. The psychiatry service determined she was not a risk to herself or others and recommended outpatient treatment for a history of depression with anxiety and post-traumatic stress disorder. The guardian also thought the patient had capacity to decide whether to go to a rehabilitation facility or home. The primary care team at the hospital, however, thought the patient was not capacitated and letting her go home would be an unsafe discharge. At this point, the guardian requested bioethics become involved.

Upon interviewing with the bioethics consultant, Mrs. L was alert and oriented to person, place, time, and problem. She voiced understanding of her decline in physical health and recognized that she did live in a home cluttered with food waste and animal excrement. She had bought a farmhouse with her husband, however, after more than thirty years of marriage to celebrate their retirement. Shortly thereafter, unfortunately, her husband had died. After his death, her daughter and son-in-law had moved in with her. She appreciated the care they provided and agreed to having all the necessary home health supports her doctors were recommending. She just wanted to go home. The bioethics consultant discussed the patient with the guardian, focusing on psychiatry's assessment that the patient seemed to be capacitated enough to decide to go home. In the end, however, Mrs. L consented to go to the rehabilitation facility which resolved the matter for the hospital and the guardian. During the patient's stay, sadly, she died, and so never was able to return home.

ETHICAL ISSUES

Despite the emergently obtained guardianship order due to what APS reported of the patient's circumstances at home, and regardless of whether or not the patient actually did have the capacity to make a fully autonomous decision to go home, the primary medical team's assessment was that she did not, and they felt duty bound to discharge the patient somewhere they felt was going to constitute a safe discharge. This case presents several ethical considerations that were further complicated by the unusual legal situation of having a court appointed guardian wish to relinquish his court appointment so quickly. First, can a medically frail and socially vulnerable patient, in this case a victim of elder abuse and self-neglect, with at best questionable decisional capacity, make a seemingly unsafe decision to go back into a neglectful environment? That is, how decisionally intact must this patient be to decide to voluntarily participate in what appears to be an abusive situa-

tion? Second, does the hospital staff have an obligation to refuse to agree with decisions that seem to have a high likelihood of leading to the demise of an at most questionably autonomous patient? Finally, who should be ultimately granted decision-making authority if a court-appointed guardian believes his ward has decisional capacity?

RECOMMENDATIONS

1. Given the legal determination of Mrs. L's incompetence (*de jure* incompetence), and the subsequent appointment of a legal guardian, she is *de facto* incapacitated and so should not be permitted to make her own medical decisions.
2. Given that she is oriented currently to person, place, time, and problem, we encourage shared decision making with her legal guardian, and other members of the medical team, a process that might be thought to move towards using a best interests standard.
3. The patient's family has acted in a manner consistent with elder abuse and therefore, they have forfeited their legal status as her caregivers.

REASONING

This case is unique due to the several ethical issues coexisting in the presence of an unclear legal situation. First, we must address the ethics questions: can a medically frail and socially vulnerable patient with limited capacity reasonably decide to voluntarily return to what appears to be an abusive situation? Also, does the hospital staff have an obligation to refuse to aid and abet decisions that will assuredly lead to the demise of a patient? Over the last 50 years, the principle of autonomy has cemented itself as a fundamental ethical principle in medical practice as the field increasingly moves away from a primarily paternalistic disposition and a system in which physicians often did not see it as their responsibility to assure informed consent.^{1,2} In theory, autonomy and paternalism are, in some ways, opposed. However, we suggest this case highlights their connectedness in ways that may be beneficial to the ethical contours of clinical practice via a best interest standard. Best interest decisions should be made based on the pain and suffering associated with an intervention, the potential for benefit, and complications that may result.³ In all situations the guardian and the medical team have a duty to respect the patient's stated wishes and preserve autonomy to the highest degree possible but also make only what they consider a safe discharge.⁴ In a system of practice that prioritizes autonomy, patients that retain the ability to provide limited informed consent for low-risk interventions (example: A moderately demented patient consenting for a blood draw but not having the capacity to consent to hemodialysis) could choose to put themselves in a situation that could lead to their own death. The UK's Mental

Capacity Act of 2005 sets out how to make health, welfare, and financial decisions for a person 16 years or older who lacks decisional capacity:

1. A person must be assumed to have capacity unless it is established that he lacks capacity.
2. A person is not to be treated as unable to make a decision unless all practicable steps to help him to do so have been taken without success.
3. A person is not to be treated as unable to make a decision merely because he makes an unwise decision.
4. An act done, or decision made, under this Act for or on behalf of a person who lacks capacity must be done, or made, in his best interests.
5. Before the act is done, or the decision is made, regard must be had to whether the purpose for which it is needed can be as effectively achieved in a way that is less restrictive of the person's rights and freedom of action.

This Act displays many similarities with the American Medical Association's code of medical ethics but goes further than the AMA code in specifying "unwise" decisions.⁵ The implication being that those who retain capacity should be free to make unwise decisions. However, those with limited capacity, those whose decisions conflict with the public interest, and those considered vulnerable for the sorts of reasons that could affect their decisional capacity, are subject to having their decisions overridden in what is argued to be their best interest.⁶ Mrs. L may have retained capacity to understand minimally to moderately complex medical interventions, however, her incompetence ruling implies that she is not fully capacitated and therefore we have an obligation to prevent her from placing herself in harmful situations. It is through the best interest standard that the above recommendations are in support of the medical staff discharging Mrs. L to a rehabilitation facility to prevent her reentering a situation of neglect and abuse.

Cases in which a legally appointed guardian makes an effort to relinquish his or her guardianship so quickly as the guardian in this case are suspected to be rare. These circumstances present confusion for the medical team. Who should be granted decision-making authority if a court appointed guardian believes his or her ward has capacity after being found incompetent? In this case, the guardian's intention to relinquish his guardianship so quickly threw the medical staff into disarray related to who should be making medical decisions. With some legal, but no ethical precedent to guide our decision making, we argued that Mrs. L's de jure incompetence overrode any level of limited capacity and recommended that decision making, no matter how upsetting to the patient, remained with Mr. K until the court released him of his duty to his ward. With this

recommendation he did consent to the patient's discharge to a rehabilitation facility. Had he chosen differently and placed the patient in a harmful situation, we believe this would have raised the following question: is hospital staff justified on the basis of a best interest standard, to reengage the court on behalf of the patient to remove a previously appointed guardian? In the American medical system this might expose the hospital network, a business entity, to legal liability and could bring an unfavorable community view of the hospital based on patient outcomes. This business risk does not outweigh the ethics benefit of providing a more protective spokesperson for a vulnerable individual in a perilous situation.

While the specific legal processes vary state to state in the United States, this case is generalizable and therefore the possibility of a similar issue arising elsewhere makes the legal complexities of this case worthy of a closer examination. But generally, to determine that a patient is incompetent to make their own decisions they must be incapable of taking proper care of themselves or their property or fail to provide for their family or other persons for whom they are charged by law to support. Once deemed incompetent, the court is tasked with providing a guardian capable of acting on behalf of the ward.⁷ A guardianship order can only be granted or terminated during a court hearing. Mr. K was an experienced guardian responsible for multiple wards. He was familiar with this process and should have known he must continue to provide for Mrs. L until such time as the court receives evidence that the underlying condition justifying the guardianship has abated. Therefore, we believe it was a deviation from court protocol for the guardian in this case to attempt to invalidate guardianship over his ward before presenting the case to the court to decide. We are only able to detail his actions and are unable to comment on his reasoning for not following standard protocol. Mr. K did retain guardianship over Mrs. L until her death.

Unfortunately, as the American population continues to grow older, more socially isolated, and medically frail, we will likely begin to care for more patients with court-appointed surrogate decision makers.^{8,9} It is important to recognize that de jure incompetence does override de facto capacity for medical decision making. However, capacity exists on a spectrum and shared decision making and best interest standards can be utilized to maximize a patient's autonomy when a patient's limited capacity is not exactly clear and, with a high degree of certainty, will lead to increased suffering and bodily harm. Medical staff will face more situations in which a patient is deemed by a court to be incompetent but is found to retain limited decision-making capacity regarding low-risk medical treatments. In those situations, medical teams will need to be diligent in assessing capacity and not override the decisions of a capacitated patient. Hospital staff and health care providers in all medical specialties will need to be critically aware of local guardianship laws in order to know how to best support the autonomy of their pa-

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Disability Paradox

The Editorial Group of the Lynch Center for Ethics

Abstract

John R., 28 years old, was admitted to Sunny Dale Hospital in the Midwest with a crushed arm from a motorcycle accident. John came through the surgery without complication and was fitted with his prosthetic arm and hand by the end of the first week, post-surgery. John continued outpatient rehab and made steady progress with his prosthesis. Many with his kind of loss never really get over the loss or find trouble adapting to their new reality. In John's case, however, he just picked up where he left off pre-amputation. Physical medicine providers tend to expect that a patient, who has a significant disability as the result of a chronic disease or injury that produces burdensome symptoms, to be seriously and negatively impacted. That is, there is an evidential mismatch between what clinicians predict will happen and what actually happens pertaining to many of their patients' experienced Quality-of-Life (QOL).¹⁻³ These patients represent the disability paradox, i.e., those who report after the disability occurs that the quality of their life is good or excellent, despite the predictions or expectations of their physical medicine providers.^{4,5}

PRESENTATION

John R., 28 years old, was admitted to Sunny Dale Hospital in the Midwest with a crushed arm from a motorcycle accident. The surgeons tried to save John's arm but it was ultimately amputated just below his elbow. To make things worse, it was his right arm, and he is right-handed.

John came through the surgery without complication and was fitted with his prosthetic arm and hand by the end of the first week, post-surgery. Within days of his prosthesis being fitted, he was transferred to Sunny Dale Hospital's Rehabilitation Center.

Because the patient had lost his right hand and lower arm, he had to learn to adapt to activities with only the use of his left hand and, simultaneously, learn to use his prosthesis. His parents, who had been at his bedside since the accident, were concerned that their son would fall into depression and be unwilling to work with the rehab team. But nothing could have been further from being the case.

John's mood had been stable throughout his care. Even when he awoke to find himself having lost his right hand and lower arm, after a day or two's adjustment, he returned to his usual good humor. From the outset, John seemed to both accept the situation and appeared quite determined to learn to use his prosthesis to its maximum potential. His parents, as well as his

physical therapy clinicians, were surprised and relieved.

His parents were also surprised at how badly John's little brother was taking John's accident. Jeremy was only 16 and every time his parents would talk about John, Jeremy would talk about how terrible the situation was. Jeremy was certain that John was going to be considered a "cripple" by his friends from now on, unable to do much and unhappy for the rest of his life.

John proved Jeremy wrong. Even though John had what the medical team considered a severe disability and expected John to have a negative reaction or suffer psychologically, this hardly ever happened. Yes, there were times during rehab when John would be frustrated with his progress and say something like, "I hate this thing on my arm. It doesn't work and I can't make it work," but shortly after his mood would lighten. John would return to making what were more often remarks such as, "I'm really close to being able to do this. With just a little more practice I'll get it." And he usually did.

After 3 weeks in rehab, John went home. John continued outpatient rehab and made steady progress improving both his dexterity and skill with his prosthesis. He eventually came to think of his prosthesis as his

“buddy,” and that they were in this together. By this point, John was back to the happy disposition that was his norm before the accident.

From the time John entered rehab, his physical therapy team was impressed by his ability to adjust to his new situation. Many with his kind of loss mourn and grieve and never really get over the loss or find trouble adapting to their new reality. In John’s case, however, he just picked up where he left off pre-amputation and kept going.

What Could Account for This, and Are There Ethical Implications?

The Disability Paradox?

The disability paradox is a data-driven, human phenomenon. Physical medicine providers tend to expect that a patient, who has a significant disability as the result of a chronic disease or injury that produces burdensome symptoms, to be seriously and negatively impacted for months or years to come. Nonetheless, many equivalently disabled patients do not experience these negative outcomes. That is, there is an evidential mismatch between what clinicians predict will happen and what actually happens pertaining to many of their patients’ experienced Quality-of-Life (QOL).¹⁻³ These patients represent the disability paradox, i.e., those who report in the weeks, months, and years after the disability occurs that the quality of their life is good or excellent, despite the predictions or expectations of their physical medicine providers.^{4,5}

The phenomenon of the ‘disability paradox’ is relatively new. The term ‘disability paradox’ was coined by Albrecht and Devlieger, building on the pioneering medical sociology work of Sol Levine.^{6,7} Empirical research is expanding and beginning to understand the phenomenon of the disability paradox.^{8,9} Some studies already show that the paradox resolves once contextual factors such as personal and environmental considerations are taken into account.¹⁰

What Causes the Disability Paradox?

Many times when patients do not react as clinicians predict, this unexpected reaction is attributed to something in the patient. And likely here, as Fellingaeuer et al. suggest, there may be personal and/or environmental factors, such as strong family support versus lack thereof, that may be influencing factors to how well patients adapt to such disabilities.

Or it may be that the data are indicative of something inherent to clinicians that is contributing to incorrect predictions. If this is the case, an ethical consideration might be that some additional self-reflection is needed by physical medicine providers. It might be, at least in some part, that clinicians are projecting their own values and beliefs onto their patients in assuming that the poor QOL they would assess for themselves, given similar circumstances, would be experienced by those patients as well. When patients have do in fact

share a poor QOL outlook, it simply matches and thus confirms physician/clinician expectations. When not, we have an instance of what has been called the disability paradox.

The literature on the role of expectation-setting is vast. Interestingly, this literature has focused heavily on teachers and school children.¹¹⁻¹³ There is, however, substantial research in the physician-patient relationship literature about physician influence on patient behavior as well.¹⁴⁻¹⁶ What this varied research tells us is that authority figures’ expectations matter.

Conclusion: Implications for Physical Medicine Providers and Their Patients

The goal, however, for most patients with disabilities is to achieve the highest functional level they can achieve. To do so it will be important for physical medicine providers and members of their hospital and rehabilitation center to not only be aware of the disability paradox, but to actively work to resolve it. One strategy is to take into account all the potentially influencing factors that may act as barriers to achieving high levels of quality of life from the point of view of the patient.¹⁷

Clinicians should be honest in their self-examination about how they would respond to the possibility that they could be disabled someday. It is a clinician’s obligation to separate personal values and beliefs from those of a patient. Although this is difficult to do, it will be important for patients attempting to rehabilitate from serious disability from chronic disease or injury, that their clinicians take a genuinely positive approach.

Understand, simultaneously, that being 100% able to either eliminate one’s own value projections completely or to predict patient response to his or her own circumstances is likely unachievable. It will be important for patients’ rehabilitation that their clinicians accept that even though power in the patient-physician relationship is invariably seated with the clinician, patient expectations may influence a clinician’s interpretation of data. It is often wise to take a position of humility towards predicting outcomes.¹⁸⁻²⁰ Neutrality in prediction may give the patient the best chance of coming out of rehabilitation with a positive attitude and self-assessed QOL.

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Communications: “But Nobody Told Us!”

The Editorial Group of the Lynch Center for Ethics

Abstract

Mrs. S is a 58-year-old woman who was born with a lung of abnormal size. As a teenager, her lung was removed. Mrs. S had done well for many years with a single lung until recently. In the last year, she has visited the hospital over a dozen times. The ICU team began speaking with the patient’s family about how Mrs. S’s condition was not sustainable and that a conversation regarding Mrs. S’s code status would be appropriate at this time. The family seemed to understand. Two days later, when the team began telling the family that the patient was now dying, they responded with shock that “no one told us she was that sick or that she was going to die!” Perhaps members of Mrs. S’s family are in denial. Ethically, this ought not be of major concern to the medical team. Nor is it the team’s obligation to attempt to break through anyone’s denial. If the team is correct and the patient is dying, then the individual who is in denial will have to ultimately face that fact after the patient’s death. What the team is obliged to state clearly is any action or actions that are taken to withdraw or withhold that which will have a material influence on the patient’s life.

PRESENTATION

Mrs. S is a 58-year-old woman who was born with a lung of abnormal size. As a teenager, her lung was removed after several incidents of collapse. Mrs. S had done well for many years with a single lung until recently. In the last year, she has visited the hospital over a dozen times. During this course, her remaining lung began to fail.

Other organs began failing as well. Mrs. S was then placed on dialysis twice weekly and was diagnosed with congestive heart failure with atrial fibrillation (AFib). Because of this combination of problems, she was not a candidate for a transplant of any variety.

The patient was now in the intensive care unit (ICU) on a ventilator. Her previously healthy lung had failed. Her liver and kidneys had not improved and were also failing. Her congestive heart failure was progressing rapidly. Just before transferring the patient to the ICU, the AHF team explained to the patient, her husband and adult children, that there was nothing more that could be done about her heart failure, that her kidneys were not recovering, and her liver failure was getting worse. Mrs. S said she was willing to be placed on a ventilator but wouldn’t talk about her wishes any further. Shortly thereafter, the patient was moved to the ICU, intubated and sedated.

The ICU team knew that Advanced Heart Failure (AHF) had already been talking to the patient’s family (the patient was too sedated to participate in care discussions) about her progressive, general decline. The physicians and nurses patiently and clearly explained that if Mrs. S’s health continued in the direction it was going, she would not survive much longer. After 3 days in the ICU, Mrs. S went into multi-organ system failure and experienced a cardiac arrest. Although a pulse was returned, another arrest was expected.

The ICU team began speaking with the patient’s family about how Mrs. S’s condition was not sustainable and that a conversation regarding Mrs. S’s code status as well as setting limitations to her care would be appropriate at this time. The family seemed to understand. Two days later, when the team began telling the family that the patient was now dying, they responded with shock and expressed that “no one told us she was that sick or that she was going to die!”

The family continued to maintain that nobody had ever told them that Mrs. S might die from her medical circumstances. When the palliative care team arrived, the family refused to speak to them because of a misunderstanding as to the role of palliation as opposed to hospice care, insisting that they didn’t believe Mrs. S was actually dying. At this point the ICU team called

for an ethics consultation. After conducting an ethical analysis of the situation, the consulting ethicist made the following recommendations.

RECOMMENDATIONS

1. Ethics recommends writing a Do-Not-Resuscitate (DNR) order.
2. Ethics recommends that an order be written capping all life-extending interventions.
3. Ethics recommends that at a regularly set time, daily, a meeting be set up for physicians to update the family and assess family members' expectations.
4. Ethics recommends not asking the family what they want to do but, rather, simply tell the family, "We are only doing things that are medically indicated to help Mrs. S."

REASONING

Clinical care has changed radically over the past century. One way it has changed is in its approach to communications around end-of-life. Today, it is orthodoxy that patients and families be given every possible piece of information about a patient's medical status.

In the case of Mrs. S, the patient and family have been kept well-informed about her progressive decline. At the point that the ICU team is telling the family that the patient is dying, and the family is protesting they have not been given any of this information, provided there has been excellent documentation of what was discussed in previous family meetings, that is sufficient. As long as one can refer back, with exact dates and dense paraphrasing to previous presentations of the contested information, doing so once or twice is sufficient to meet one's professional responsibilities.

It is usually at this point that the team starts talking, among themselves, about the patient and/or family as being "in denial." Denial is the conscious refusal to perceive or acknowledge that painful facts exist. Denial is a defense mechanism, among a list of defenses, that comes out of the psychoanalytic work of Sigmund Freud. Denial, it is postulated, protects one from intolerable feelings, thoughts, or events. Unless excessive, denial, like other defense mechanisms, is considered part of normal, human, psychological function.¹

Perhaps members of Mrs. S's family are in denial. Ethically, this ought not be of major concern to the medical team. The team's ethical obligation is to inform the patient's surrogate (her husband in this case) and family (with the surrogate's permission) that the patient is dying in clear terms. It is also the team's obligation to document clearly and specifically the provision of such information.

If the medical team is clear and comprehensive in communicating that Mrs. S is in fact dying, it is not the team's obligation to repetitively provide that infor-

mation. Doing so can feel, in the surrogate's and other family members' experience, like being bludgeoned with sensitive information.

Nor is it the team's obligation to attempt to break through anyone's denial. If the team is correct and the patient is dying, then the individual who is in denial will have to ultimately face that fact after the patient's death. What the team is obliged to state clearly is any action or actions that are taken to withdraw or withhold that which will have a material influence on the patient's life, including CPR.²

Often when denial is suspected by clinicians it does not actually exist. The patient and/or family are often well aware of the medical circumstances and/or whether the patient is dying, but not want to be forced by clinicians into making decisions they don't feel ready to make.

This may be the point at which the team would benefit from invoking a standardized check list of other information and assistance to be offered. Items on this check list include such matters as reminding the family, gently, that the hospital will arrange for a second opinion or assist in a transfer (unlikely, but sometimes helpful in having a family agree with the treating team that the patient is at her end). Going through such steps assures a measure of procedural justice adheres to patient care and goes a long way in avoiding arbitrariness.

What obligations remain are summed up in the 15th century folk saying, reiterated by the 19th century physician, founder and tuberculosis (TB) patient, Edward Livingston Trudeau, of the TB sanitarium at Saranac Lake, Adirondacks, New York.^{3,4} "To cure sometimes, to relieve often, and to comfort always." Given that Mrs. S's discernable pain and/or discomfort is being managed medically, those left that require comforting are her husband and children. That comfort requires that systemic pressures for reducing excessive length of stay are resisted and that the family is carefully heard.

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