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At the Bedside

- 167 How We May Become Detached from Our Patients and What We Can Do If This Happens
Edmund G. Howe

Features

- 179 Deathbed Confession: When a Dying Patient Confesses to Murder: Clinical, Ethical, and Legal Implications
Laura Tincknell, Anne O'Callaghan, Joanna Manning, and Phillipa Malpas
- 185 Ethical Challenges in Acute Evaluation of Suspected Psychogenic Stroke Mimics
Alexandra J. Sequeira, Michael G. Fara, and Ariane Lewis
- 191 Positive HIV Test Results from Deceased Organ Donors: Should We Disclose to Next of Kin?
Anne L. Dalle Ave and David M. Shaw
- 196 Posthumous HIV Disclosure and Relational Rupture
Laura K. Guidry-Grimes and D. Micah Hester

- 201 Plain Anabaptists and Healthcare Ethics
James Benedict

- 206 Refusal of Vaccination: A Test to Balance Societal and Individual Interests
Kavita Shah Arora, Jane Morris, and Allan J. Jacobs

- 217 Nursing Ethics Huddles to Decrease Moral Distress among Nurses in the Intensive Care Unit
Marianne C. Chiafery, Patrick Hopkins, Sally A. Norton, and Margie Hodges Shaw

- 227 "I Would Do It All Over Again": Cherishing Time and the Absence of Regret in Continuing a Pregnancy after a Life-Limiting Diagnosis
Charlotte Wool, Rana Limbo, and Erin M. Denney-Koelsch

Perspectives

- 237 The Mission of Safety Net Hospitals: Charity or Equity?
Thea James

- 240 Scribes, Electronic Health Records, and the Expectation of Confidentiality
Paul M. Wangenheim

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6 West Washington Street, Suite 302, Hagerstown, Maryland 21740 USA

240-420-8850 • fax: 240-718-7100

jce@clinicaethics.com

www.clinicaethics.com

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At the Bedside

How We May Become Detached from Our Patients and What We Can Do If This Happens

Edmund G. Howe

ABSTRACT

When clinicians provide clinical care or participate in ethics consultations, they may feel exceptionally painful emotions. When they do, they may distance themselves emotionally from patients and families. This distancing may harm these parties profoundly. It is therefore critical that clinicians avoid this distancing. In this piece, I present an approach that lies outside traditional practice that clinicians may use to try to avoid and even reverse this distancing, if and when they sense that this may be occurring. This approach may also benefit patients and families. It may increase their sense that their clinicians are working with them as allies to achieve their shared medical goals.

In introducing this issue of *The Journal of Clinical Ethics*, I shall discuss how we may best respond to patients and families when we become exceptionally emotionally distressed. In our medical training, we are taught to try to feel appropriate detached concern. This involves our, on the one hand, feeling empathy for our patients, but, on the other, remain-

ing sufficiently detached so that we can continue to be able to give our patients the optimal care that they need. Balancing these competing objectives may be difficult, and sometimes impossible. In some cases, for example, our emotional pain may overwhelm us. Then we are more vulnerable to becoming emotionally detached from our patients. Further, this detachment may occur even when we do not intend or want this to happen. It may occur automatically, outside our awareness, as if to protect us from painful feelings we could find too much to bear.

This detachment may greatly harm patients. It may hasten or even precipitate their death, as is most clear in the case of suicide. I present, therefore, an approach we may use to prevent this distancing from occurring. It may, in addition to stopping emotional distancing, possibly reverse it. It may result in patients feeling closer to us. Patients may see us more as allies, working with them to accomplish common medical goals, rather than seeing us as caring for them because this is just what we do.

This approach involves sharing our feelings with our patients when we feel overwhelmed, and disclosing too why this is. This makes our patients more knowledgeable about what is going on within us and, more importantly, unites patients and clinicians in searching for the best solutions together. Patients may feel greater closeness because we have been willing to share the angst we feel in these exceptional situations. Patients might see that we are distressed, already, in any case.

Edmund G. Howe, MD, JD, is Professor of Psychiatry and Director of Programs in Medical Ethics at the Uniformed Services University of the Health Sciences in Bethesda, Maryland; and Editor in Chief of *The Journal of Clinical Ethics*. The opinions or assertions contained herein are the private views of the authors and are not necessarily those of the AFRRI, USUHS, or the Department of Defense. The funders had no role in study design, data collection, and analysis; decision to publish; or preparation of the manuscript. Conflicts of interest: none.

There are other approaches we can use to try to reduce our emotional detachment from patients. Some are the same ways that we can use to try to avoid feeling burned out, as, for example, reducing our stress through activities such as meditation or jogging. These strategies, however, may not go far in enabling us to avoid emotional distancing and help us to continue to feel close to patients, and they to us. The emotions we experience when we treat some patients may simply be too much for us to bear. Then, consciously or unconsciously, we may distance ourselves from them to gain needed relief.

We may need another, better way to gain relief, as I will suggest. It may be uncommon, but it is not unprecedented, even though it lies outside and may go against traditional teaching. It may help us remain emotionally close to our patients when we perform the role of clinician or ethics consultant.

Two articles in this issue of *JCE* present cases that illustrate how emotional distancing can occur. From these cases I shall draw paradigmatic examples. The first article, "Ethical Challenges in Acute Evaluation of Suspected Psychogenic Stroke Mimics," by Alexandra J. Sequeira, Michael G. Fara, and Ariane Lewis, presents the case of a 47-year-old man who is admitted to the hospital complaining of 30 minutes of left-sided weakness.¹ If he is having a stroke, administration of tPA (tissue plasminogen activator) will be lifesaving, if it is administered in 4.5 hours. The patient's weakness comes and goes and may be psychologically caused. If he is not having a stroke, tPA poses only a small risk, but requires a high-acuity setting and significant use of resources. The hospital physician is uncertain, and may feel helpless. Feelings of uncertainty and helplessness are feelings I shall discuss as paradigms of the feelings that cause clinicians to emotionally distance themselves from patients.

The second article in this issue of *JCE* that I will discuss, "Deathbed Confession: When a Dying Patient Confesses to Murder: Clinical, Ethical, and Legal Implications," by Laura Ticknell, Anne O'Callaghan, Joanna Manning, and Phillipa Malpas, presents a case illustrating an emotion that may cause us to distance ourselves emotionally: *shame*.² The clinicians in this case may have felt shame and may have distanced themselves from the patient because they may have felt that they had to betray him and violate his confidentiality, although they had implicitly promised him that they would not.

Emotional distancing may protect us from pain that is caused by uncertainty, helplessness, and shame—and other painful feelings. This emotional distancing may occur automatically and wholly

outside our conscious awareness. Feelings of fear may exacerbate this distancing.³

The approach I suggest is to share the emotional pain we feel with patients, before we begin to distance ourselves from them. In response to powerful emotions, some clinicians may find themselves spontaneously crying in the presence of a patient. In doing this, clinicians may be acknowledging what the patient already knows they are feeling, but, by making their feelings explicit, they are including the patient, as though the patient was a member of their own family.⁴ This may bring patients and clinicians closer, which may be critically important to some patients, as I will discuss later. I will discuss the feelings of uncertainty, helplessness, and shame as paradigms. After discussing each of the feelings, I shall suggest how we might directly present these feelings to our patients, with a verbatim example.

UNCERTAINTY

Feelings of uncertainty may cause us to emotionally detach from patients, especially when the stakes are high.⁵ Clinicians who feel uncertain may respond sub-optimally in other important ways.⁶ We may, for example, conduct unnecessary tests.⁷ We may even, more ominously, discriminate among patients, based on their race.⁸

The case of the patient with left-sided weakness who may have been having a stroke, described above, left the physician feeling uncertain and perhaps even helpless. He could not resolve his uncertainty, but still had to act. He may have felt helpless because he had no way to discern whether the patient was really having a stroke. Fortunately, the stroke treatment would not have been fatal if the patient was not having a stroke. But often this is not the case. One example is when patients are suicidal. A second example is when infants are born so prematurely that it is almost inevitable that they will die, or, if they live, they will not "walk, talk, or relate" (as this is sometimes expressed). In both of these contexts, we may feel highly uncertain, and the stakes are irreducibly high. I shall use these two examples, patients who are chronically suicidal, and newborns who are extremely premature, to illustrate how we may be able to share our feelings of uncertainty with patients (and parents) to reduce the possibility we will distance ourselves emotionally from them.⁹

Patients Who Are Chronically Suicidal

When patients may commit suicide, we may feel especially uncertain because we (rightly) feel a need to be as certain as we can about how to best help

them. Feelings of uncertainty in such high-risk contexts are painful. Further, like all people, clinicians can be susceptible to irrational beliefs. Since the outcome of suicide is never inevitable, then, in theory, any suicide might be prevented. Thus, we may be vulnerable—in spite of knowing otherwise—to feel that we could have prevented a patient from taking his or her life, even when this isn't truly the case. When patients are chronically suicidal, if we hospitalize them against their will (or even just try to), it may harm them more than not doing it, over the longer run. Patients who are so hospitalized, for instance, may find it so traumatic that they choose to not see a mental health provider ever again.¹⁰ The trauma that some patients experience in the hospital may be greater if they are given medication by injection against their will. Patients who have been hospitalized and who are suicidal are more prone to taking their life in the month or so after they are released, perhaps reflecting the pain they report that they experience during hospitalization.¹¹

The effect on the patient/clinician relationship from even trying to involuntarily hospitalize such patients may be just as harmful to our patients, or even worse. Our relationship may, in some instances, be all that is keeping patients alive. When we treat patients who are chronically suicidal, we may be in a bind. On one hand, we want to help them do optimally over the long run. Yet, at the same time, we may accurately fear that if we don't hospitalize them immediately when their suicidal feelings increase, they may be at an increased risk of taking their life.¹²

There are other options. For example, we can meet more frequently with patients when they are more suicidal. One such patient and I agreed under these circumstances, for example, to talk by phone, initially, every six hours. We were then able to decrease the frequency. He has done well. But even waiting between such a patient's phone calls can cause us to feel highly uncertain. It still evokes fear. When we feel fear, it is likely to affect all that we do. For example, when we take an initial history from a patient, if suddenly the patient says he or she feels suicidal, our interaction may change, from that very moment. We may always have at the back of our mind the fear that this patient may take her or his life. As a result, we may change what we do in our therapy. We may spend less time seeking to give the patient the skills she or he will need over a longer time, and instead spend more of our time together asking the patient whether he or she feels suicidal.¹³

In addition, we may detach from the patient and not recognize that this detaching is occurring. We may rationalize decisions to distance ourselves as

being warranted for other reasons. For example, we may believe that the patient is exaggerating suicidal feelings to obtain more therapy than the patient is entitled to and needs. If we distance ourselves emotionally and share these thoughts with the patient, it may result in the patient feeling more suicidal.

This is an instance in which sharing our painful feelings may help us remain emotionally close with a patient. We can explain that the problem is within us. "I am emotionally torn," we might say, "because I want to help you in every way that I can, but at the same time the number of sessions we can have is, as you know, supposed to be limited. I feel so torn, not knowing what we should do." We can add, "If I thought I needed more treatment, this is something I can imagine that I would want to do for myself."

We could add that we know that the persons who will review the patient's need to have additional sessions may question and even turn down the request, and may do so because they believe the patient may not be suicidal, but is saying this to be able to have more therapy sessions. We could say that we suspect that may happen, because reviewers have responded in that way before. We can say that the last thing we would want to do is to respond in a way that would leave the patient feeling he or she must try to make the case that he or she is genuinely suicidal. We can say that if we feel the patient needs further sessions, we can imagine we would want to do whatever we could to do this. We can share this to make clear that we hurt and especially because we understand it to be the irresolvable nature of the patient's core plights. Sharing this may benefit the patient and our relationship, regardless of what we decide together at that time, or what we decide later, if we must decide this alone.

Since we may have to make a decision unilaterally, we should make this clear from the start: "I don't know now whether I will request more sessions. I will have to decide. I feel very torn and would like to discuss why with you. But I can imagine that if I were you, I might just want to say to me, 'So . . . decide!' Would you like me to share with you why my making this decision is so difficult for me?" As a result of saying this, as we face making the decision with our patient, we are more equal with the patient. The patient is more informed, and, to the degree that both parties are facing making a decision, greater *allies*. It may be that we will decide to not request more sessions. After our sharing our feelings and our plight, we still have to act independently, but we have disclosed this, and thus have involved our patient in the process, to the degree that we can.

When we don't distance ourselves emotionally from our patients, but stay emotionally closer to them, they may come to feel, over time, that they can find the kind of meaning they experience with us in interaction with others. It may be that, for some patients, the only way in which they can acquire a hope that they can experience a relationship with others is by first experiencing this openness and honestly with their clinician.

This process of sharing more with our patients may include sharing any rifts that come between us. If we can survive these rifts and still feel close to our patients, it may help them to be able to conclude that having a life of quality and meaning, shared with others, may be possible.¹⁴ An example may be helpful to illustrate how coping together with a patient, through such a rift, by talking it out, may be possible. This example also illustrates how subtle yet pernicious emotional distancing can be. I was seeing a patient who had felt chronically suicidal for years before I first saw him. A college rugby player, he had repeatedly reassured me that, as he hadn't taken his life, despite feeling chronically suicidal, he wouldn't. Rather, he often shared with me how important it was to him to share with me how much he wanted to die, since he had not been able to share this with anyone previously. Despite this reassurance, once as he was describing this wish in what seemed to be especially vivid terms, I panicked. I then asked him the customary question to screen for acute suicidality and the possible need for voluntary or possibly even involuntary hospitalization. He recognized this change immediately, and told me he felt angry. Hadn't he reassured me enough, he said, that he wouldn't take his life? I shared with him that I'd felt frightened, and said that I was sorry. I added that I was, in one sense, *glad*, because at least he now had a ground for believing that it might be that I genuinely cared. He had told me before that he had thought that all of the prior clinicians he had seen did what they did for the money. He said he was sorry he had scared me. This I took as an indication that he had an important strength: he could, I inferred from this, look at himself, see how he had affected me, and respond in a way that was optimal and most interpersonally appropriate. This indicates how such a rift may be talked out and resolved.

But there is more here to consider: my use of the word "appropriate." This is accurate, but at the same time reflects my judgment of this patient. Thus, in even my just thinking this, I may have moved from being primarily another person, to being primarily a clinician assessing a patient and judging his progress. Patients may sense this and find it infantilizing. When clinicians do this, we may con-

note to patients—rightly or wrongly—that we regard ourselves as superior, and this may quash the thread of a relationship we have with each other. This is an illustration of the subtlety with which we can distance ourselves emotionally from our patients, and possibly, as a result, end a meaningful relationship with them. It illustrates how we may never be able to not distance ourselves from patients as we treat them, since we must, at some point, view them objectively, for example, when we measure if they are getting better. The goal is, rather, aspirational and asymptotic. We can seek to relate with our patients as fellow humans; for example we will both experience death. Yet, as clinicians, we cannot but view them, in a sense, as our project, whom it is our task to make better. As this is the case, what can we do? We could share even this with our patients.

To be more specific: How could share what we feel with a chronically suicidal patient? We could say, "I am terrified that you could take your life and I don't know at all what I should do. I may have to consult with others, and they may determine that I should hospitalize you, even if I don't agree. If they—or they and I—believe we must hospitalize you, even though we know you don't want this, please know I feel greatly sorry. We might do this even knowing how strongly you oppose it, because we believe this is necessary now to best insure that you don't take your life. If we decide this, we may be wrong, and I feel terribly bad now, knowing I don't know what is best for you." This example is greatly compressed for purpose of this illustration. In a real interaction, we should then ask the patient how she or he responds to this, and discuss it, if the patient wants to. Our hope is that even if, in the end, we disagree with the patient, that we have shared our feelings and the competing rationales might result in the patient's later having a greater understanding. This may allow a greater alliance with the patient than might otherwise be the case.

Extremely Premature Newborns

Infants who are born extremely prematurely may do well, or they may die or survive greatly impaired. Like the parents of such infants, clinicians may feel most uncertain about what to do.¹⁵ With the stakes as high as they are, our fear, too, is as high as it gets. Like parents, we may not know whether we should fully treat these infants.¹⁶ Some clinicians may believe, however, that in rare cases, we should make decisions on our own, without involving parents.¹⁷

That is, in rare cases when an infant who is born extremely prematurely will almost certainly die, or, if the infant survives, will be most severely neurologically impaired, some clinicians may not ask the

parents to be involved in making a decision whether to begin or continue to fully treat the infant, because the clinicians may see the infant as having an almost inevitably dismal and extremely poor prognosis, regardless of what is done.¹⁸ These infants will, the clinicians believe, die and/or not be able to talk, walk, or relate.¹⁹ With this exceptionally poor prognosis, the clinicians believe that to ask the parents to decide with them what they should do would be not only unacceptably misleading, but cruel. Asking parents to participate in making decisions could imply that there are real choices to be made, when there are none.²⁰

We can first talk with parents and indicate that we may decide that we should make decisions unilaterally because there are no real choices. On hearing this, parents, even when consulted fully from the outset, may feel enraged.²¹ There may be a case to be made that we could at least share with parents how badly we feel about this. When considering whether or not to say this, a consideration is that later parents may remember and value it.²²

We can also ask how far in explaining the bases of our angst we should go. If, having asked parents whether they want to know about how decisions will be made, and the parents say they would, we might ask them whether they want to know more about the questions staff will consider as they decide what they should do. If parents want to know more about this, we can share some of the ethical questions around how decisions should best be made. There are many; for example, making a decision could involve only neonatologists, only neonatologists and pediatricians, or both of these groups and obstetricians.²³ It could also involve nurses and other staff.

Then there are other questions: How many should be involved in making a decision? Should a decision be unanimous, or by a majority, or decided in some other way? If a decision is to be made by majority vote, should the voting be made anonymously?²⁴ These questions apply to decisions regarding extremely premature infants everywhere. Less-common questions are whether the parents want to know about the staff's shared pain, especially if the staff feels it must make these decisions unilaterally. When we struggle emotionally to answer these questions, we can take the initiative to offer parents the opportunity to discuss that—at the time, or later.

This may be seen as an extension of what we share when we cry with a patient, as I noted above. In the case of parents of an extremely premature infant, sharing our feelings may enable them feel that we are “side-by-side” with them.²⁵ As Norman Quist wrote, citing the pediatrician and psychoanalyst D.W. Winnecott in a past issue of *JCE*, “a sign of

health in the mind is the ability of one individual to enter imaginatively and yet accurately into the thoughts and feelings and hopes and fears of another person; also to allow the other person to do the same to us.”²⁶

If decision making will be shared with parents, we may seek to decrease any emotional distancing we may experience by going further than we would otherwise. Here is one example to illustrate how this might be done. With both parents present, prior to making any decision, we can ask them whether they want to discuss with us what they would want to do, if they have different views than we do. We could point out that having differing views is almost inevitable. If the parents want to discuss this, we can consider together how different values and decisions might affect the relationship that they have with us in the future. We might add that this may affect their infant, as well.

These discussions and the concerns expressed during the discussions may differ widely, depending on whether the parents are married and/or doing well, or are just hoping to do well. If the parents are married and doing well, for example, a key question to discuss with them might be, in addition to what might be best for the infant, what decisions may best allow their good relationship to continue to thrive and survive. If the parents aren't married, but one parent wants to be married more than the other parent does, there is a risk that the parent who wants the relationship to continue and grow may be tempted to go along with whatever the other parent wants, in the hope that this will increase the likelihood that the relationship will continue.

If we don't have these communication skills or don't have the time for these discussions, but the parents want this, we can contact others who have the skills and the time. Both of these initiatives—asking parents if they want to discuss making decisions and finding a way that they can, if they do—may directly offset emotional distancing, which may occur in this context if we have different views than parents.

When we decide by ourselves whether or not to include parents in making treatment decisions, to share our feelings, we might say, “What happens here may be close to unbearable for you. It is for me too, although to an infinitely less extent.” Expressing the feeling we have is depicted by Quist, who quotes Jerome Groopman. Groopman describes telling his patient, Maxine, that she has a disorder that may cause her death. “Maxine, sobbing, says to Groopman, ‘I don't want to die. . . . I didn't think it would happen so fast, so soon. I'm not ready to die.’ Groopman replies, ‘I don't want to lose you.’”²⁷

HELPLESSNESS

In the case of the patient who might have been having a stroke, discussed above, the physician making treatment decisions probably felt helpless. He had no way to discern whether the patient was having a stroke or had a conversion disorder. Helplessness is one of the most painful, if not the most painful, emotions we can feel. When we feel helpless, in any context, we may become emotionally detached. We may feel this in a wide variety of circumstances, as when a patient has an incurable cancer. Here are some less well-known examples of how clinicians who do not want to distance themselves emotionally may want to proceed.

Subtle Examples That May Evoke Feelings of Helplessness

Helplessness may be very painful for clinicians because we need to feel certain and able to help in order to best treat our patients. There are some contexts, however, in which the opposite may be true. For instance, hospice clinicians can't save patients from dying, but they can help patients as they die, to an almost an immeasurable extent.

Hospice clinicians help their patients find and feel meaning in their life. In their last weeks and days, some patients find new meaning, and some find more than they ever had before. This new and greater meaning comes from mostly having deep or deeper interactions with others. Clinicians of all kinds can have these deeper interactions too. A patient may remember one word or even a gesture from us. One way to achieve this is to share our feelings when we feel helpless. We may, as clinicians, be not only prone to hiding painful feelings of helplessness, but to distancing ourselves from patients when we feel that way. An example that can be used as a paradigm to discuss this is the hospital physician in the case considered above, whose patient had left-side weakness, and may have been having a stroke. On the other hand, this patient might have had a *conversion disorder*, a psychologically caused condition whose cause can't be seen.²⁸ In cases like this, we may deal with our own pain at feeling helpless by blaming the patient. Thus, we may think or say with some disrespect that the patient's pain is all in the head. Most of us know by now not to do this. Yet this response indicates an emotional defense we have against the more painful feeling of helplessness, to which we are all still prone.

This response occurs especially when patients have symptoms for which we can find no bodily cause.²⁹ We may believe, irrationally, that if patients really wanted to, they could change. More often than

not, they cannot change, at least not on their own. Nonetheless, we distance ourselves. This error can occur when a loved one commits suicide. Afterwards, we may blame ourselves because we think we could have prevented it, if we were in the right place at the right time—but we weren't. We may believe only what we can see, and so, when we see patients with a psychogenic disorder, such as a conversion disorder, we may wrongly conclude that they can change by choosing to do so, just as we may wrongly conclude that because we might have been able to prevent a suicide, we not only plausibly could have, but should have.

The hospital staff caring for the patient with left-side weakness saw this psychogenic possibility and accepted the patient as he was, and didn't judge. We may experience feelings of helplessness when a patient has pain we can't fix, and then we may, in addition to blaming the patient, detach emotionally from the patient to even an even greater extent because we believe, to some degree, perhaps rightly, that the patient may be seeking drugs.

Another example is patients with anorexia nervosa. It may seem that they won't eat when they could and should. This may cause us to blame them and distance ourselves emotionally. The number of patients who die from this disorder is frightening. This risk emphasizes the importance of not distancing ourselves emotionally with these patients, but instead to increase our relationship with them. How might we possibly do this better? We might, when we feel helpless, share that information. In the next section I will discuss the possible, perhaps not so obvious, gains from sharing even these feelings.

Possible Gains from Sharing Feelings of Helplessness

I have presented the possible benefits of sharing the pain we experience with our patients. If we do this, we should always first share with our patients that we absolutely "get" that they are doing everything they can to get well. We may not know for sure that they are doing everything they can to get well, but we can assume they are, and say so. And when we do know for sure that they aren't, we can, transparently, explain our reasons.

The critical factor we must keep in mind when we do this is that there may be a reason patients are not doing what they can to get better. When we want to retain and preserve our relationship with such patients, we must recognize and make explicit that even if we don't know the reason they are not doing something to get better, we know that there *is* a reason, whether or not this is within their conscious control. When we share our angst at feeling help-

less, it is likely that our patients feel angst at feeling helpless, as well. It is critically important that we say we know that they lack conscious control, because doing this validates that there is nothing they can do, and indicates that we know this. Sharing our feelings of helplessness with patients before sharing our other thoughts may be necessary for patients to be able to be open to hearing our thoughts, and for the thoughts to be able to “go down.”

An example is patients who have a symptom such as pain, from which they get a so-called secondary gain, and they retain the secondary gain only if they keep the symptom. For example, the gain may be money that compensates the patient for an injury caused by another person. Compensation for the pain may continue only if the pain and the limitations it causes persists. How might we best proceed in these situations? The best approach is to prioritize our relationship with patients.³⁰ First, we can acknowledge why we feel helpless and how painful it is, and why we are sharing this with them. We can say that we imagine that they are in pain, even with this secondary gain, and that they are feeling much more helpless than we are. Thus, from the first moment we share this, the patients are not blamed, and, with the feelings we share with them, we are together, and less distant from one another in this way.

We may also help patients feel more equal by sharing with them how their symptoms may be outside their conscious control. Here I rely on the scientist Joseph LeDoux, whose empirical research explains how some information may get laid down in a person’s brain without the person knowing this is happening.³¹ For example, we may watch a frightening scene in a video for fractions of a second, too short for us to be able to take note of it. Our bodily processes, such as blood pressure and our heart rate, may, however, change at that moment, indicating we saw the frightening scene, even though we have no awareness that we did. We had a “fight or flight” response even when unaware that we had it. The memory, however, remains and may affect us.

Sharing our feelings of helplessness with such patients, and going the extra mile to explain why, may, over time, help them to get better, although why this happens is not yet known. There is another way to help patients fare better when they feel helpless that is not new, but is an enhanced old way. This approach was pioneered by psychiatrist James L. Griffith, who has since taught it to other clinicians to help patients who feel helpless on hospital wards.³² Griffith walks clinicians through sequential steps. First he asks them how they coped best in the past when they were in closely parallel, helpless conditions. For example, some clinicians who

feel burned out will do best through an activity such as jogging or gaining the help of others. Griffith seeks specifics. If clinicians say they were helped by others, he inquires, “Has this been a former mentor or a trusted friend to whom you can ventilate?” Likewise, we can seek to brainstorm with patients how they can implement a past choice that worked well.

What specifically might we say to patients when we want to share our feelings of helplessness? We might say, “I want to help you as much as I possibly can. Now, however, medically, I am helpless. Medicine has no way I can tell for sure whether you are [having a stroke/a conversion disorder/having the pain that you are]. For me it is terrible being helpless, and I can imagine, for you, your pain is many times this. Let me explain what we can still do under these circumstances.”

SHAME

Another article in this issue of *JCE* that I want to discuss is “Deathbed Confession: When a Dying Patient Confesses to Murder: Clinical, Ethical, and Legal Implications.” Ticknell, O’Callaghan, Manning, and Malpas present the case of a terminally ill patient who confesses that, decades before, he performed “several contract killings” as a gang member. The medical staff is torn. They want to respect their patient’s confidentiality—as they do for all of their patients—but they also want to help the families and loved ones of those who were killed, to help give them closure, in case they don’t know what happened to their loved one. The staff are faced with conflicting duties: to respect their professional and personal implicit promise to the patient, and to help others. They may distance themselves emotionally from the patient, as a response. This kind of conflict exists in many contexts in medicine, and I will now consider conflicts in similar contexts and suggest what we may do in response.

Similar Contexts

As they cared for the former gang member, now a patient, the medical team may have felt anticipatory shame. That is, they may have felt shame at merely wondering whether they should renege on their promise to protect the patient, as breaking this promise would violate their deepest moral beliefs. To reduce the pain of this shame, they may have emotionally detached themselves from him.

In regard to this and similar cases, it may be best to first consider an ethical possibility that may warrant priority over all other moral frameworks and principles: that this patient, notwithstanding what he did in the past, may be worst-off. If so, perhaps

meeting his needs should be the first priority for the team, unless another competing interest is especially compelling; for example, in this case, the needs of his victims' loved ones might be given priority. To put this metaphorically, it may be that the bully needs us more than the bullied. And this may pertain, whether or not the patient knows this.

Why? This patient may be so blocked off or emotionally numbed by what he has experienced that he now feels no needs, even though he may still have them, and at some level is hurting. He may, for example, feel totally and abysmally alone. This may be the kind of a rock-hard emotional defense that some people show when they have complete denial. People may, on the other hand, feel neither the need for caring from others nor regret. Yet we never can know this. Some patients, for example, do not say so much as a word to a new clinician, even after seeing the clinician for weeks. The clinician may sit with the patient, silently, day after day. Then suddenly the patient talks to the clinician. And weeps.

Some therapists work with incarcerated patients who will never go free, since they are serving a sentence with no possibility of parole. With therapy, the patients, who may be bitter and want nothing for years, may come to find, to their surprise, that even though they are confined in prison for the rest of their life, there is still much meaning in life, and that they want to live. The reason for this? It may be the relationship they have with their therapist.

These ethical considerations support giving due moral weight and ethical priority to the patient who had been a gang member, regardless of what he had done. But whether we can actually "get there" ethically or emotionally is discussed in the next section. The need to help others who have done wrong, and the shame this may cause when others' interests are in conflict, may appear in many guises. This occurred for me, most painfully, when a patient came into my office in extreme emotional distress. He had done something wrong. He was no longer a danger to others, but we both knew it was likely that one of us would have to turn him in. He turned himself in, and now, long after, he is finally well.

The painful angst I experienced was as strong as I have ever felt for a patient. I imagine the staffs' feelings around the former gang member were as painful. I still wonder whether I should have said something to my patient such as, "I expect that it may be that one of us should turn you in. I feel terrible about the thought of doing this. I feel this in part because I care so much for you, as I hope you know. I wouldn't have known about this if you hadn't told me. I fear that since this is the case, I should turn you in, but I am too chicken. I lack the courage

to be willing to follow through with this thought." The fear is greater and the stakes are higher when others are in danger, or when others may be helped by our actions.

Another patient caused me similar, although less intense, angst because I thought (rightly or wrongly) that I knew him better than I actually did. This patient had taken a medication with a known side-effect, causing him to imagine harming others. I could have and perhaps should have called in the police, or at least should have said I would do this unless he admitted himself to the hospital. I did not call the police, perhaps because I imagined my ability to predict his future behavior was greater than it was. But thankfully, his impulses to do harm went away and he, too, has since done well.³³

A more ominous example is that of an adolescent boy on a school bus, who shared, when riding home with a fellow student, that he felt like killing his teacher. His fellow student reported this to the school principal. The principal sought the advice of the school guidance counselor. The counselor consulted two different mental health professionals who differed radically in their recommendation. One thought an in-house evaluation at the school might suffice to clarify that the student did not pose a genuine risk. The other thought that any action short of immediate hospitalization and evaluation of the student would run an unacceptable risk. The guidance counselor and the principal decided to conduct an evaluation in-house, and it was determined that the student did not pose a risk. He said he had not really meant the threat. Those who met with the student, like the members of the team who cared for the former gang member, worried over their determinations greatly.

How might we help our patients, whether or not we violate their confidentiality or some other duty owed to them? Our chief task may be, at all costs, not to distance ourselves emotionally from them. I shall now discuss how this might best be done.

Sharing Despite Ethical and Emotional Reservations

There are two issues that make it difficult or implausible for us to treat some patients. We may have ethical or emotional objections that are so strong we cannot realistically expect to treat them effectively. In this last section, I shall address these two objections, and how to help our patients if we have these objections and want to overcome them.

Ethical objections. Throughout time, people have seen wrongs as warranting punishment and have sought revenge. Thus, retribution remains a rationale underlying our laws, even today. Emotionally, too, we may crave revenge. As clinicians, we

may have these feelings, notwithstanding what our professional oaths urge us implicitly to think and say. We can use ethical analysis to assess and determine how these general guidelines should best be applied. This may be the most that ethics has to offer. If we do this in an attempt to discern what *other clinicians* should do in these instances, we will have a tough row to hoe. This is because our ethical views and emotional convictions may differ from other clinicians', and thus make it hard or even impossible for us to do what we conclude they should do.

Do people who have committed wrongs, such as the patient who murdered, have free will at the time? What of those who murder for pay? Is there any line we could and should reasonably draw? If these persons have free will, to what extent do they have it, and should this matter? Even if these people knew at the time what they were doing, and did these things deliberately, is there a place in our society to forgive them, or, if not, for us as clinicians to forgive them? These questions are irreconcilably controversial and complex. It may be that this disagreement and complexity shouldn't matter to us, as clinicians. Our duty to help all patients, as our oaths urge and require us to do, may, morally, be quite right in these instances.

In regard to questions involving free will, we might consider the case of Leslie Van Houten, one of the women who committed murders at the direction of Charles Manson.³⁴ At the time of the Manson trials, Margaret T. Singer, a clinical psychologist, was widely viewed as a leading expert on cults and on how people could be brainwashed by them.³⁵ The brainwashing used by cults, Singer said, surpasses even those that enemies use during wartime. Cults, for example, flood new members with love and, at the same, time keep them isolated and away from all those they know. A particularly pathognomonic characteristic that cult members tend to show and that mark them as possibly brainwashed is how they respond to questions of all sorts with the same answer. They tend to respond with Johnny-one-note answers, as it were, suggesting that they are like a needle on a phonograph record stuck in one groove, able to play only one snippet of melody over and over. Singer testified at Van Houten's trial that when Van Houten repeatedly stabbed her victim, she had been brainwashed by Manson and thus at that time was not able to freely choose what she did.³⁶

This example is only one among hundreds, and may be anomalous. Still, it indicates how having free will may not be as self-evidently unequivocal as we might think. Our inner judgement may be absolute in some cases, and difficult to shake, but our awareness of people like Van Houten and Singer's

view of them may make it more possible when we treat them to give them more the benefit of the doubt.

Moving from the question of free will; in the case of the patient who committed murders as a gang member, the staff decided what to do primarily by weighing and balancing the pros and cons of maintaining his confidentiality. This is a more traditional moral framework, weighing various ethical principles. The staff instead might have accorded priority to maintaining the quality of their relationship with the patient, following an ethics of care. This moral framework could have produced a profoundly different outcome, as illustrated by one of its advocates, Nel Noddings, who once stated that she would lie, at any time, for her son. Her special relationship with him, she said, required this response.³⁷

In using an ethics of care, we may see ourselves as owing greater loyalty to our patients, overriding other, competing moral values, much as Noddings saw her chief priority as being caring toward her son. Utilitarianism is another ethical framework, which, in theory at least, one can use to quantify an ethical response. That is, with this approach, one can seek to add up numbers to determine an ethical response, which makes it an approach that is easily defended. For that reason, it may be overused.

Put most simply, we are at risk of opting too readily to make ethical decisions on the basis of utilitarian calculations and consequences when other values, not based on consequences, should prevail. These values may not be easily quantified and easily defended, such as respecting persons and being just. Other frameworks that emphasize relationships are among those that might prevail.

If, in the case of the patient who had killed many others, the medical team used more of an ethics-of-care approach, their analysis might have been different. They might have placed more moral weight on respecting the patient's confidentiality, and, on the basis of his being, beneath it all, one of the worst-off, as already mentioned.

Emotional objections. Even if we can ethically come to terms with what patients like these have done, we may still not be able to move beyond our emotional responses to them. We may *feel*, for example, repugnance, or feel that they are evil. Whether there are people who are evil, or whether evil is a description of what people do, may be, like free will, a philosophical question that will remain and never reflect a consensus.³⁸ There are ways, though, we can reduce these feelings, if we want, so we are able to treat these patients. To assist clinicians who feel emotions like repugnance, based on their patients having "done evil," I shall present three approaches we can use.

A first approach begins with the awareness that these patients may have gone through past experiences that we haven't and quite literally, perhaps, couldn't even imagine. I think of a young person who survived after an ambush of everyone on a bus, in another country. He survived because he lay hidden and wholly silent under the dead bodies of others. Much later, as an adult, he committed a crime in the United States, when, he says, he "was triggered" in response to another's actions. Another example is a person who, as a teen in another country, was captured with his family and was told by his captors that he was to kill his family, or the captors would kill them all. We may not easily be able to fathom, much less imagine, what some of our patients have experienced. Even if they have not undergone exceptional stress, they may be more vulnerable to profoundly upsetting reactions to the smallest of stresses, and in that way differ greatly from most other people. For example, in some people, the bones that form the skull and surround the brain may be unusually fragile, such that a blow to the skull is much more likely to shatter the skull. In forensic settings this is referred to as eggshell skull. It may be a genetic condition.

A second approach to reducing our repugnant feelings toward some patients is to imagine, as best we can, tendencies within ourselves that mirror those we see in these patients. We widely, if not universally, have a tendency to see those traits that we least like in ourselves as not there in us at all, but as existing in others. We project the traits we abhor to others. None in us, but only in them. For example, I can identify within myself the feeling of wanting revenge. I see this because I know that when I hear that others who have hurt me have, in some way, fared not as well as they could, inside I feel the glimmer of a gloat. If we are, to this extent, able to see how we are like these patients in this way, we may be able to feel empathy and relate, to a degree, sufficiently for us to be able to treat and help them.

A third approach, urged by Paul Ricoeur, may help us to "slice through ethical Gordian knots."³⁹ Ricoeur had profound losses and pain during the Holocaust. Still, he supported only going forward and doing good. What mattered to Ricoeur was not the act that was committed, but the suffering of the victim. Thus, what counts is not what happened, but what one still can do. Ricoeur's focus, then, was on relieving and preventing further suffering. Likewise, we can take this same approach, reasoning that if he and so many others *could* do good—and *did*—so can we. But merely clearing these ethical and emotional impediments to be able to help patients like

the former gang member, however, will not help us to go far enough to help our patients, or to even reach them at all. To do this it may be necessary for us to somehow convince patients that we really care about them. This may mean that to reach some patients, we must do more than we usually would.

An approach that may do this as much as any other is to share the emotional pain we are feeling. This has been found to reach patients in other exceptional contexts, such as patients who feel emotionally empty, when others do not. The best argument for such emotional sharing was made by the psychiatrist Hugh Mullan.⁴⁰ He suggested that, for patients to change in the ways they want, therapists must be themselves and discard the emotionally distancing aspects of the therapeutic role. Mullan "eschewed" a "mechanized, linear view of the person." He believed that psychotherapy is, in essence, the "life-changing emotional meeting between vulnerable humans (both patient and therapist) who communicated one with another."⁴¹ More concretely, he believed that, to help patients change, therapists must change themselves. The patient's change, he thought, "is *contingent* on change in the therapist."

In treating these patients, feeling emotional pain is inevitable. Whether or not we decide to respect their confidentiality, they are likely to be harmed by our distancing ourselves from them.⁴² How might we best avoid that? We might begin by saying what may be most important to them: that we will strive mightily to put their interests first, but there may be limits to what we can do, that we should have foreseen, but didn't. We might say:

If we come to decide to not respect your confidentiality, and violate it to benefit another person, you may understandably hate us and not want to speak to us again. But please know that I, just saying this, feel greatly torn, even though I know that my pain is very much less than yours. Regardless of what our staff decides to do, you may feel deeply hurt, even livid in response to my telling you that we are even considering this. Please know also, that even though I know you may be feeling this way, I would like and hope very much to stay with you and work with you after this, regardless of what we or the staff decide, if this is at all what you would want. You needn't decide this now, and at any time you could change your mind.

CONCLUSION

When we have painful feelings that our patients evoke in us, we may emotionally detach from them.

I have discussed how we may seek to avoid this by sharing directly with patients the pain we feel. Disclosing this pain extends to the wider population of all patients, and includes what we share when we cry with patients.

I think of an illustration made by Elvin Semrad, a revered psychiatrist at Harvard.⁴³ A resident was crying because, he said, a patient wasn't doing at all well. "Let him see you as you are now," Semrad, said, in essence. The resident then "confessed his distress and helplessness to his patient, and told her he desperately wanted to help her, but did not know how."⁴⁴ She, then, did better.

MASKING

Details in the cases have been altered to protect the identities of patients and family members.

NOTES

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1. A.J. Sequeira, M.G. Fara, and A. Lewis, "Ethical Challenges in Acute Evaluation of Suspected Psychogenic Stroke Mimics," in this issue of *The Journal of Clinical Ethics* 29, no. 3 (Fall 2018).

2. L. Tincknell, A. O'Callaghan, J. Manning, and P. Malpas, "Deathbed Confession: When a Dying Patient Confesses to Murder: Clinical, Ethical, and Legal Implications," in this issue of *The Journal of Clinical Ethics* 29, no. 3 (Fall 2018).

3. M.C. Nussbaum, *The Monarchy of Fear* (New York: Simon & Schuster, 2018); K. Kozłowska, P. Waler, L. Mclean, and P. Carrive, "Fear and the Defense Cascade: Clinical Implications and Management," *Harvard Review of Psychiatry* 23, no. 4 (July-August 2015): 263-87.

4. J. Fox, "'Notice How You Feel,' An Alternative to Detached Concern Among Hospice Volunteers," *Qualitative Health Research* 16, no. 7 (September 2006): 944-61.

5. M.J. Dugs, M.H. Freeston, and R. Ladouceur, "Intolerance of Uncertainty and Problem Orientation in Worry," *Cognitive Therapy and Research* 21, no. 6 (1997): 591-606.

6. Portnoy and colleagues note, "our findings provide preliminary evidence that physicians' perceptions of patients AA [ambiguity aversion] may influence physicians to adopt paternalistic practices and to forgo communicating with patients about scientific uncertainty . . . and involving them in decision making. This might paradoxically and counterproductively *increase* patients' uncertainty. . . ." Emphasis added. D.B. Portnoy et al., "Physicians' Attitudes about Communicating and Managing Scientific Uncertainty Differ by Perceived Ambiguity Aversion of their Patients," *Health Expectations* 16 (2011): 362-72, 369.

7. E.P. Tubbs, J.A. Elrod, and D.R. Flum, "Risk Taking

and Tolerance of Uncertainty: Implications for Surgeons," *Journal of Surgical Research* 131, no. 1 (March 2006): 1-6.

8. B.A. Cunningham et al., "Physicians' Anxiety Due to Uncertainty and Use of Race in Medical Decision-Making," *American Public Health Association Medical Care Section* 52, no. 8 (August 2014): 728-33.

9. L. Diamond-Brown, "The Doctor-Patient Relationship as a Toolkit for Uncertain Clinical Decisions," *Social Science and Medicine* 159 (2016): 108-15.

10. D.T. Chung, C.J. Ryan, and M.M. Large, "Commentary: Adverse Experiences in Psychiatric Hospitals Might Be the Cause of Some Post Discharge Suicides," *Bulletin of the Menninger Clinic* 80, no. 4 (Fall 2016): 371-5.

11. M. Olfson et al., "Short-term Suicide Risk After Psychiatric Hospital Discharge," *JAMA Psychiatry* 7, no. 3 (November 2016): 1119-26. See also T.P. Ho, "The Suicide Risk of Discharged Psychiatric Patients," *Journal of Clinical Psychiatry* 64, no. 6 (2003): 702-7.

12. Patients may take their life in the hospital. As one psychiatrist says, however, this could be prevented by keeping every patient in restraints, but then few might get better.

13. "The suicidal patient who for long periods of time remains mute is particularly prone to become the target of projected countertransference hate." J.T. Maltzberger and D.H. Buie, "Countertransference Hate in Suicidal Patients," *Archives of General Psychiatry* 30 (May 1974): 625-33, 629.

14. "We must expect collisions and *withstand and contain* . . . their impact on the relationship. . . ." L. Havens, "The Best Kept Secret: How to Form an Effective Alliance," *Harvard Review of Psychiatry* 12 (2004): 1256-62, 1258.

15. M.R. Mercurio, "The Ethics of Newborn Resuscitation," *Seminars in Perinatology* 33, no. 6 (December 2009): 354-63.

16. Statistical predictions regarding how an infant will do may be inaccurate because existing studies have excluded infants who were given only palliative care. P.D. Murray, D. Esserman, and M.R. Mercury, "In What Circumstances Will a Neonatologist Decide a Patient is Not a Resuscitation Candidate?" *Journal of Medical Ethics* 42 (2016): 429-34. In this study, of 490 practicing neonatologists, 25 percent responded "yes" when asked if a unilateral DNAR (do not attempt resuscitation) would be permissible based solely on neurological prognosis.

17. Clinicians may believe that medical expertise and experience necessarily bring about ethical expertise, but this may not be the case. Thus, a more senior clinician who may be a department chair may too much determine a staff's decision. Likewise, staff members may not fully share their different views because they don't want not to offend the friends they will be working with the next day and days.

18. In the U.S., when clinicians feel they cannot provide futile care to a child, they generally offer parents the opportunity to try to find other hospitals that will. A. Park, "When Parents and Doctors Disagree on What Futile Means," *Time* (24 July 2017): 17-8, 17.

19. The severity of an infant's status when she or he can't talk, walk, or relate is subject to different responses. In my own experience, some parents love such children

as much or more than any child who has these capacities.

20. Parents may, on the other hand, be allowed to decide that only one of a set of twins will be resuscitated. M.J. Bizarro and M.R. Mercurio, "Selective Resuscitation in Premature Twins: An Ethical Analysis," *Journal of Perinatology* 29, no. 7 (July 2009): 479-82; A. Hurst et al., "Tough Decisions for Premature Triplets," *Pediatrics* 137, no. 2 (February 2016): e20153804, doi:10.1542/peds.2015-3804.

21. Clinicians may tend to underestimate the meaning that many parents find in holding their baby, even though they know that soon the baby will die. Clinicians also may tend to underestimate the quality of life of an infant and its parents when the infant is more severely impaired. A. Janvier, K. Barrington, and B. Farlow, "Communication with Parents Concerning Withholding or Withdrawing of Life-Sustaining Interventions in Neonatology," *Seminars in Perinatology* 38 (2014): 38-46, 43.

22. D. Nuzum, S. Meaney, and K. O'Donoghue, "The Impact of Stillbirth on Consultant Obstetrician Gynaecologists: a Quantitative Study," *British Journal of Obstetrics and Gynaecology* 121, no. 8 (July 2014): 1020-8.

23. B.T. Edmonds et al., "Comparing Obstetricians' and Neonatologists' Approaches to Periviable Counseling," *Journal of Perinatology* 35 (2015): 344-8.

24. M.R. Mercurio, "The Role of a Pediatric Ethics Committee in the Newborn Intensive Care Unit," *Journal of Perinatology* 31, no.1 (January 2011): 1-9.

25. Parents may ask their clinician, "What would you do?" Clinicians who routinely respond, "I can't say," may want to reconsider this. Some patients value greatly hearing their clinician's view. Clinicians' not sharing this may also lessen patients' trust in their relationship. Janvier, Barrington, and Farlow, "Communication with Parents," see note 21 above, p. 41.

26. N. Quist, "The Paradox of Questions and Answers: Possibilities for a Doctor-Patient Relationship," *The Journal of Clinical Ethics* 14, no. 1/2 (Spring/Summer 2003): 79-87.

27. Ibid.

28. P.I. Rosebush and M.F. Mazurek, "Treatment of Conversion in the 21st Century: Have We Moved Beyond the Couch?" *Current Treatment Options in Neurology* 13 (2011): 255-66.

29. A conversion disorder that is likely to evoke clinicians' anger is when a patient has blindness. The patient may still somehow step around obstacles that clinicians purposefully place in the way to help them make this diagnosis. F. Scarpina et al., "Explicit and Implicit Components of the Emotional Processing in Non-organic Vision Loss: Behavioral Evidence About the Role of Fear in Functional Blindness," *Frontiers in Psychology* 9 (10 April 2018): 494 doi: 10.3389/fpsyg.2018.00494. eCollection 2018.

30. I have observed that therapists may disclose their emotions to a greater extent to patients who have dissociative disorders. (These patients experience disconnection and lack of continuity in their thoughts, memories, surroundings, actions, and identity, escaping reality in involuntary and unhealthy ways.) This may be because

therapists must offer more of themselves to be able to reach and help these patients.

31. J. Le Doux, *Anxious* (New York: Viking, 2015). See also J. LeDoux, R. Brown, D. Pine, and S. Hofmann, "Know Thyself: Well-Being and Subjective Experience," *Cerebrum* (January 2018): 1-15; http://www.dana.org/Cerebrum/2018/Know_Thyself_Well_Being_and_Subjective_Experience.

32. J.L. Griffith, "Hope Modules: Brief Psychotherapeutic Interventions to Counter Demoralization from Stressors of Chronic Illness," *Academic Psychiatry* 42, no. 1 (February 2018): 135-45.

33. M. Chapman, "A Review of Violence Risk Assessment for the General Clinician," *Psychiatric Annals* 47, no. 9 (2017): 449-53.

34. N. Meredith, *The Manson Women and Me* (New York: Citadel, 2018), 126-32.

35. A. O'Connor, "Margaret Singer, a Leading Brainwashing Expert, Dies at 82," *New York Times*, 7 December 2003, <https://www.nytimes.com/2003/12/07/us/margaret-singer-a-leading-brainwashing-expert-dies-at-82.html>.

36. K. Faith, *The Long Prison Journey of Leslie Van Houten* (Lebanon, N.H: Northeastern University Press, 2001).

37. N. Noddings, *Caring*, 2nd ed. (Berkeley, Calif.: University of California Press, 2003), 56-57.

38. R. Simon, "Should Forensic Psychiatrists Testify About Evil?" *Journal of the American Academy of Psychiatry and the Law* 31, no. 4 (2003): 413-6.

39. P. Ricoeur and D. Pellauer, "Evil, a Challenge to Philosophy and Theology," *Journal of the American Academy of Religion* 53, no. 4 (December 1985): 635-48. For a discussion of Ricoeur's views at this time, see S. Paulika, "How Should We Respond to 'Evil'?" *New York Times*, 27 June 2016, <https://www.nytimes.com/2016/06/27/opinion/how-should-we-respond-to-evil.html>.

40. F. Wright, "Personal Reflections on Hugh Mullan: Existential Group Therapist," *International Journal of Group Psychotherapy* 62, no. 1 (January 2012): 23-42. In a similar approach called "presentness," the emphasis is on "mutual reverie and moments of spontaneous responsiveness on the part of the therapist." R. Lazar, "Presentness: an Intersubjective Dimension of the Therapeutic Act," *American Journal of Psychotherapy* 54, no. 3 (Summer 2000): 340-54.

41. Wright, "Personal Reflections," see note 40 above.

42. For a study reporting that shame uniquely predicts avoidance and distancing, see T. Schmader and B. Lickel, "The Approach and Avoidance Function of Guilt and Shame Emotions: Comparing Reactions to Self-Caused and Other-Caused Wrongdoing," *Motivation and Emotions* 30, no. 1 (March 2006): 43-56.

43. M.L. Good, "Elvin V. Semrad (1909-1976): Experiencing the Heart and Core of Psychotherapy Training," *American Journal of Psychotherapy* 63, no. 2 (2009): 183-205.

44. J.T. Maltzberger, "Treating the Suicidal Patient: Basic Principles," *Annals of the New York Academy of Science* 932 (May 2001): 158-68, 160-1.

Features

Deathbed Confession: When a Dying Patient Confesses to Murder: Clinical, Ethical, and Legal Implications

Laura Tincknell, Anne O'Callaghan, Joanna Manning, and Phillipa Malpas

ABSTRACT

During an initial palliative care assessment, a dying man discloses that he had killed several people whilst a young man. The junior doctor, to whom he revealed his story, consulted with senior palliative care colleagues. It was agreed that legal advice would be sought on the issue of breaching the man's confidentiality. Two legal opinions conflicted with each other. A decision was made by the clinical team not to inform the police.

In this article the junior doctor, the palliative medicine specialist, a medical ethicist, and a lawyer consider the case from their various perspectives.

Laura Tincknell, Bsc, MBBS, is Palliative Care Registrar at Auckland City Hospital in Auckland, New Zealand. Lauratincknell@doctors.org.uk

Anne O'Callaghan, MBBS, MRCP, FACHPM, EdD, is a Palliative Medicine Consultant at Auckland City Hospital, and a Senior Lecturer in the Faculty of Medical and Health Sciences, University of Auckland. a.ocallaghan@auckland.ac.nz

Joanna Manning, BA, LLB(Hons), MA, is a Barrister and Solicitor of the High Court of New Zealand, and Professor at the Faculty of Law at the University of Auckland. j.manning@auckland.ac.nz

Phillipa Malpas, PhD, is an Associate Professor in the Department of Psychological Medicine, Faculty of Medical and Health Sciences, University of Auckland. p.malpas@auckland.ac.nz

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INTRODUCTION

During an initial palliative care assessment, a dying 70-year-old man, in physical pain and existential distress, disclosed he had killed many people when he was a young man. Prior to his disclosure he asked what would happen to any information he revealed.

In this article the junior doctor, the palliative medicine specialist, a medical ethicist, and a lawyer consider the case from their various perspectives.

Consideration of the case offers no easy or satisfying answers. It is a powerful and compelling example of the doctor-patient relationship in action in clinical practice and illuminates particular challenges for health practitioners working with patients at the end of life.

THE CASE

EF was a 70-year-old man with advanced metastatic cancer. On his final admission to hospital he was referred to the palliative care service for difficulty with pain control. He was frail, in severe pain, could no longer get out of bed, was not eating or drinking much, and needed full nursing care.

During the initial palliative care assessment, EF complained of severe pain. He stated that he believed

he was at the end of his life and wished to discuss his life and some of the choices he had made. At the commencement of his story, he asked what would happen to the information he gave. It was explained that the information would not be disclosed unless it was thought he was at risk of doing himself or someone else harm.

He revealed he had become involved as a young man in gang culture and had performed “several contract killings” 50 years previously. He knew little of the people whom he had killed, but he thought the bodies of some of these people may not have been found. He spoke of guilt at the lives he had cut short and of the families who may not have known what happened to a loved one. He reflected on his own situation: “I looked into their eyes—saw fear and pulled the trigger. The problem for me is now someone else has the gun and I am the one who is afraid. I always pulled the trigger first—but now I can’t.”

In his mid-20s he had served a prison sentence for accessory to murder. Following release he joined the merchant navy, stating that he had had to kill people in this line of work as well as to protect his boat and other crew members from acts of piracy.

On returning home after a few years at sea he felt he was a reformed character, and spent the next 40 years of his life trying to atone for what he had done with charitable works, monetary donations to good causes, and taking on “lost souls” to help them turn their lives around.

The conversation focussed on his feelings and emotions, with very little factual information given about the crimes. As he talked he had a remarkable transformation, becoming calm and measured with obvious relief showing in his voice and body language. The next day he was out of bed, walking and eating, and over the coming days his analgesic requirements fell significantly.

Following the consultation, the palliative care team sought advice from personal liability insurance lawyers and the hospital lawyers. The advice was conflicting. The personal liability opinion was that the individual practitioner had no legal obligation to disclose information about crimes that happened 50 years previously—citing New Zealand Health Information Privacy Code, Rule 11(2)(d)¹—and that disclosure without express consent from the patient opened up the practitioners to complaint. Hospital legal advice was that “consent had been implied” by the patient’s disclosure of the information, and therefore the police should be informed.

On follow up visits, EF remained pleased to have “confessed” and spoke of relief. He did not want to revisit the conversation and he did not give consent

for the information to be shared. He was willing to talk about what to do with his knowledge, and decided he would write a letter detailing information relevant to his past crimes to be given to the police following his death. He did not want help with writing and insisted he would do it in his own time. He was offered, but declined, access to additional psychological and/or spiritual support.

He died at a residential facility six weeks after discharge from the hospital. He did not discuss his disclosure with the community palliative care team and it is not known whether he left a letter.

THE PALLIATIVE CARE SPECIALIST’S PERSPECTIVE

Knowledge of the approach of death can precipitate an existential crisis. The existential crisis may be manifest in a number of ways, including a worsening of physical symptoms, and is often conceptualized as “total pain,” as described by Cicely Saunders.² The provision of effective palliative care thus means that practitioners should not only be experts in symptom control but should also have, or be able to access, skills in the psychological and spiritual domains, in order to relieve existential distress.³ Work in the spiritual domain is often described as a process of making sense, making meaning, and making peace.⁴ It may be best supported through establishing a therapeutic relationship based on trust and respect.⁵

In palliative care, when time might be short, effective relief of suffering is more likely to result when the practitioner has the capacity to form an effective therapeutic alliance with a patient in a short space of time, as occurred with this case.

In relation to EF, his physical condition was such that the admitting team, the palliative care team, and the patient all expected death to occur within a few days. His condition, however, improved following a palliative care consultation in which he was able to reveal his fears and regrets. Facing his own death triggered the memory of his experience of killing others and a need to “confess” to events that had occurred 50 years earlier. Revealing his actions, and also his 40-year attempts to atone for these, resulted in relief of both his physical pain and his anguished mental state.

As EF’s death was expected to be imminent, the focus of care was on relieving his pain and distress and on capturing, if possible, any information about his crimes that might be of benefit to anyone. He did not consent to disclose details of his crimes to the palliative care team or to anyone else, but as it

became apparent that he might survive to be discharged to a nursing home, he agreed to document specific details to be revealed after his death. At the same time urgent legal opinions were sought, specifically whether the confession should be revealed to the police. The team attempted to balance the possible risks versus benefits in breaking confidentiality. The risk of disclosure, at worst, was that the therapeutic relationship between the patient and his healthcare providers would be lost with a recurrence of his distress, worsened through a sense of betrayal, resulting in a difficult death. This was coupled with the likelihood that he was deemed to be unlikely to reveal anything to the police that would incriminate himself. The benefit of disclosure, at best, was that he would agree to provide details of his crimes to the police, which might result in closure for some remaining relatives or friends of those whom he had killed. The legal opinions provided conflicting advice, and in particular the hospital legal opinion that “consent had been implied” differed from the view of the clinical teams.

After lengthy discussions, an uneasy decision was made not to inform the police. This was based on an assessment at the time of likelihood of harm versus likelihood of benefit. Had the crimes occurred more recently, had EF shown the slightest desire to use official channels to “make good” his deeds, and had he not been assessed as dying very soon, the decision might have been different. The case led to a desire to more fully explore the ethical and legal perspectives of disclosure both before and after death.

THE ETHICIST'S PERSPECTIVE

At the heart of this compelling case lies the ethical challenge of whether information given in confidence to a health practitioner ought to be disclosed to a third party without the patient's consent. Should confidentiality trump disclosure, and, if so, on what grounds?

Confidentiality sits as a cornerstone of medical practice and is in effect when an individual discloses information to another, either through words or actions, and the person who is given the information vows not to divulge it without the individual's consent.⁶ Medical confidentiality generally finds its justification in a utilitarian framework of cost-benefit analysis—it is said that keeping patients' information confidential allows patients to speak freely and openly, thus ensuring appropriate and timely medical treatment. It has been argued that if patients could not trust health practitioners to keep information

confidential, patients may not be willing to disclose significant information that may have an adverse impact on their subsequent medical treatment and care.

EF disclosed serious information within a therapeutic relationship bound by trust and confidence. He recognized the seriousness of the information by asking, prior to his disclosure, what would happen to it. He was assured that unless someone was at risk of imminent harm (including EF), the information would be kept confidential within the palliative care team. On that basis, he disclosed the information.

The principle of confidentiality, however, is not absolute. The New Zealand Medical Association *Health Information Privacy Code* allows health practitioners to disclose information about a patient in a limited range of circumstances, including when disclosure “is necessary to prevent or lessen a serious and imminent threat to—(i) public health or safety; or (ii) the life or health of the individual concerned or another individual.”⁷

Would breaking EF's confidence (prior to his death) be ethically mandated? There are compelling reasons to think it is. First, an allegation of murder is serious and has profound implications for others. Most obviously, the murder victims suffered the ultimate harm in being killed. Moreover, was someone else convicted for the murders EF alleged that he committed? Second, we might think further that the victims' families have a right to know this information, as it is pertinent to them. Finally, some may claim that EF should be held to account and punished for his crimes. These are valid and sound reasons to consider disclosing such information to the police; however, I believe that breaching confidentiality whilst EF remained alive would be unethical.

The doctor-patient relationship, exemplified by trust and honesty, is central to ethical analysis of the case. In this case EF spoke of his past actions only when assured that his confidence would not be broken. Asking EF several days later about what should be done with the information exemplified respect for him and involved him in the dilemma the doctor faced. EF clearly stated that he did not wish to repeat the conversation with anyone else. If the police were told of EF's confession against EF's will, it was possible that EF would deny the allegations, potentially thwarting any further investigation. The palliative care team would then be left with a dying patient whose confidence had been violated and who might have refused to have anything further to do with them. They might have also face disci-

plinary action if a complaint was brought against them as a result of the disclosure.

Keeping EF's confidence and encouraging him to write down details of his crimes in a letter to be opened after his death might have resulted in far greater beneficial consequences than reporting his confession to the police. Even if such a letter was unable to identify victims, an investigation might have provided clarity on the crimes, the location of victim's remains, and might have offered the victims' families some resolution.

But what if no letter was written? Should the details have been disclosed to the police postmortem, or should EF's confidence be held evermore? I believe disclosure—postmortem—was ethically permissible. First, EF was in agreement with the idea of writing a letter in the days following his disclosure to, and discussion with, his doctor. He took responsibility for his past actions, and his decision to write a confessional letter suggested he was acting autonomously and with intent. His consent to disclose was strongly implied by these conversations and strengthened by his admission that he lived with the knowledge of what he did every day, and had spent more than half of his life attempting to repent for his actions. Given the seriousness of the crimes he committed and the harms suffered by others as a result, the moral obligation to disclose the information to the police should take precedence over any possible diminution of EF's memory.

Ethical analysis strongly supported keeping EF's confidence based on the bounds of the therapeutic relationship. Once that relationship was severed through EF's death, and given EF's desire to acknowledge his crimes, the interests of those harmed by EF's actions would justify the clinician's disclosure to the relevant authorities.

THE LAWYER'S PERSPECTIVE

The palliative care team were permitted to disclose EF's identity and any details of the "contract killings" in his youth to the police after his death without attracting legal liability.

It is an uncontroversial legal rule that a health professional owes a legal obligation of confidentiality to a patient, "whether he be a model citizen or murderer."⁸ The key legal risks to the team from unauthorized disclosure were civil actions for breach of the duty of confidence and the tort of unreasonable interference with privacy,⁹ complaint to New Zealand's Privacy Commissioner, and professional disciplinary proceedings. The privacy of medical information receives further protection in the United

Kingdom from the human right to "respect for private and family life," but courts must balance it against the conflicting right of "freedom of expression."¹⁰ Proportionate interference with each of these is permitted in the interests of (among other things) public safety, the prevention of disorder or crime, the protection of health, and the protection of the rights and freedoms of others.¹¹ Some jurisdictions have added additional legislative protections. New Zealand's Health Information Privacy Code (HIPC),¹² for example, generally prohibits health practitioners from disclosing an individual's health information.

In this case, establishing *prima facie* cases of breach of confidence and interference with privacy in the event of disclosure presented little difficulty. The information disclosed was obviously private and sensitive; its release could have both beneficial and negative consequences for others, such as surviving family or friends of EF himself or his victims. He unburdened himself only on being given an assurance of confidentiality, and reiterated that wish. The revelations were made in the context of a relationship understood by all to be confidential. The obligation is not restricted to medical information, but extends to any private information imparted in circumstances imposing an obligation of confidence. A civil claim of invasion of privacy requires proof that publicity given to private facts would be considered highly offensive to a reasonable person. Although the "highly objectionable" criterion prescribes an objective test, it is to be applied from the perspective of a reasonable person in EF's position.¹³ One can readily envision the feelings of betrayal, distress, and fear that a person in EF's shoes might reasonably experience, had he learned before his death of disclosure against his wish, for example.

Although disclosure can now no longer harm EF, the ethical and professional duties continue after death.¹⁴ Guidance from the U.K. General Medical Council is: "If the patient had asked for information to remain confidential [after their death], you should usually respect their wishes."¹⁵ What little law there is on the point favors the legal obligation as also surviving the patient's death.¹⁶ The time for which it persists depends on factors such as the nature of the relationship, the nature of the information, and any harm that may be caused by disclosure to the deceased's estate or those she or he may have reasonably wanted to protect.¹⁷ EF's death was recent; he confided information when in extremis and in the context of a close therapeutic relationship. The information was sensitive, and could cause significant harm to his memory and distress to his surviving family and friends. A court would prob-

ably conclude that the team was still bound by its legal obligation.

The duty of confidence is not absolute. The only legal justifications for disclosure are that the patient consented, or where the public interest in disclosure outweighs the public interest produced by keeping the confidence.¹⁸ Hospital legal advice was that EF implied consent to disclosure, presumably on the basis of his expressions of guilt and concern for his victims' families, consist with his intention to write a letter. But the law maintains a tight rein on implied consent, and will not imply it if it is inconsistent with the patient's express wishes, which are generally binding. EF refused consent to disclosure expressly and repeatedly.

A well-known public interest justification for disclosure, plainly inapplicable since EF presented no physical risk even before his death, is to prevent a serious and imminent threat to public health or safety or the life or health of an individual.¹⁹ "There is no confidence as to the disclosure of iniquity," proclaimed Wood VC in *Gartside v. Outram*.²⁰ This refers to another recognized public interest justification: when disclosure is necessary to avoid prejudice to the maintenance of the law, including the prevention, detection, investigation, prosecution, and punishment of offenses.²¹ The justification applies to past crime that has gone undetected and unpunished, as well as to crimes and misdeeds in contemplation. EF was not about to commit further crimes before death, and if he did, he could have been brought to justice. Disclosure could only assist the investigation and detection of his past crimes. This could, on occasion, also be of compelling public interest, however. Disclosure would likely promote the welfare of any surviving family of EF's victims, who might have benefitted from psychological closure from the identification of EF as the perpetrator, and the possible location of his victims' remains. And investigation and detection of criminal misconduct, even if unpunished because of the perpetrator's death, expresses powerfully society's condemnation of criminal wrongdoing and sense of solidarity with its victims, as well as sending a deterrent signal to others contemplating similar offenses that they risk punishment.²²

The team was permitted, but not obliged, to disclose.²³ The discretion was exercised, taking into account ethical and professional obligations. Professional guidance recommended that a crime had to be sufficiently serious for the public interest to prevail; the likelihood that the crime would be solved with disclosure was also relevant.²⁴ Although the few factual details EF provided suggested that dis-

closure might not have significantly assisted police investigations, new forensic technologies, such as DNA profiling, might have permitted connection of him to the killings. The "contract killings" occurred long ago, and were unsolved. Without disclosure, there was no imperative for the police to reopen these "cold cases."

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BLINDING OF THE CASE

Details of the case were altered to protect the identity of the patient.

NOTES

1. [New Zealand] Health Information Privacy Code, Rule 11(2)(d), October 2008, <https://www.privacy.org.nz/assets/Files/Codes-of-Practice-materials/Health-Information-Privacy-Code-1994-plus-amendments.pdf>.
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6. T. Beauchamp and J. Childress, *Principles of Biomedical Ethics*, 6th ed. (Oxford, U.K.: Oxford University Press, 2009), 302-7.
7. [New Zealand] Office of the Privacy Commissioner, "Health Information Privacy Code 1994," Rule 10 (1)(d): 1-108, <https://www.privacy.org.nz/assets/Files/Codes-of-Practice-materials/HIPC-1994-2008-revised-edition.pdf>.
8. *Ashworth Security Hospital v. MGN Ltd* [2000] 1 WLR 515, 527.
9. The privacy tort is recognized in some jurisdictions, including New Zealand; see *Hosking v. Runting* [2003] 3 NZLR 383 (CA), but is rejected in the U.K., see *Wainwright v. Home Office* [2003] 2 AC 406.
10. See [U.K.] Human Rights Act 1998, Schedule 1, articles 8(1) & 10(1), <https://www.legislation.gov.uk/ukpga/1998/42/schedule/1>.

11. See [U.K.] Human Rights Act 1998, Schedule 1, articles 8(2) & 10(2), <https://www.legislation.gov.uk/ukpga/1998/42/schedule/1>.

12. See note 7 above.

13. *P v. D* [2000] 3 NZLR 391, para 39.

14. See the Hippocratic Oath, https://www.nlm.nih.gov/hmd/greek/greek_oath.html; New Zealand Medical Association, "Code of Ethics," Principle 5, https://www.nzma.org.nz/__data/assets/pdf_file/0016/31435/NZMA-Code-of-Ethics-2014-A4.pdf; [U.K.] General Medical Council, Confidentiality, 2009, para 70, <https://www.gmc-uk.org/ethical-guidance/ethical-guidance-for-doctors/confidentiality>.

15. *Ibid.*

16. *Bluck v. Information Commissioner* [2007] 98 BMLR 1; *Lewis v. Secretary of State for Health* [2008] EWHC 2196.

17. *Ibid.*

18. *A-G v. Guardian Newspapers (No 2)* [1990] AC 109, 282.

19. See [New Zealand] Privacy Commissioner, "HIPC, Rule 11(2)," <https://www.privacy.org.nz/assets/Files/Codes-of-Practice-materials/Health-Information-Privacy-Code-1994-plus-amendments.pdf>; *W v. Egdell* [1990] 1 All ER 835.

20. *Gartside v. Outram* (1856) 26 LJ Ch 113, 114.

21. [New Zealand] Privacy Commissioner, "HIPC, Rule 11(2)," see note 18 above; *Malone v. Commissioner of Police* [1979] 2 All ER 620, 634.

22. See generally, J.A. Hughes and M. Jonas, "Time and Crime: Which Cold-Case Investigations Should Be Re-heated?" *Criminal Justice Ethics* 34 (2015): 18-41.

23. If they chose to disclose, they would be advised to disclose only information of EF's past crimes and only to the police, and on condition that the information was used only for investigation purposes.

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Ethical Challenges in Acute Evaluation of Suspected Psychogenic Stroke Mimics

Alexandra J. Sequeira, Michael G. Fara, and Ariane Lewis

ABSTRACT

Tissue plasminogen activator (tPA) is administered to patients with suspected ischemic stroke to improve blood flow to the brain. In rare cases, patients present with complaints of stroke symptoms that appear to be non-organic due to malingering, factitious disorder, or conversion disorder (psychogenic stroke mimics). Deciding whether or not to administer tPA to these patients can be challenging. The risk of hemorrhage after administration of tPA is low, but not zero. The ethical principles of beneficence and non-maleficence need to be weighed carefully in these situations. We present two cases of patients with suspected psychogenic stroke mimics to illustrate the ethical challenges faced in identifying and managing psychogenic stroke mimics. Further research is needed to demonstrate effective treatment strategies for patients with acute stroke symptoms of psychogenic etiology.

Alexandra J. Sequeira, MD, MSc, was a Resident in the Department of Neurology at New York University Langone Medical Center in New York, New York, when this article was written. alexandra.lloydsmith@gmail.com

Michael G. Fara, MD, PhD, was a Resident in the Department of Neurology at New York University Langone Medical Center when this article was written.

Ariane Lewis, MD, is an Associate Professor in the Department of Neurology and an Associate Professor in the Department of Neurosurgery at New York University Langone Medical Center. ©2018 by *The Journal of Clinical Ethics*. All rights reserved.

INTRODUCTION

When faced with an acute medical management decision, such as the decision whether or not to administer tissue plasminogen activator (tPA) to a patient with suspected ischemic stroke, physicians are sometimes confronted by an ethical dilemma. On the one hand, we are guided by the principle of beneficence to do what we can to help our patients. As such, unless a patient is at increased risk of bleeding, it is the standard of care to give tPA to a patient with suspected ischemic stroke in an effort to ameliorate his or her symptoms if the patient presents within four and one-half hours of onset of symptoms.¹ However, we are also guided by the principle of nonmaleficence, to avoid causing unnecessary harm to our patients. When a patient presents with stroke symptoms that are thought to potentially be psychogenic (that is, symptoms that are the result of psychopathology rather than the result of poor blood flow to the brain), these principles can come into conflict, forcing the physician to quickly decide whether the potential to help the patient if her or his symptoms are in fact due to stroke is greater than the potential to harm the patient if her or his symptoms are psychogenic.

In the outpatient setting, one-third of neurology patients have a non-organic etiology of their symp-

toms,² but psychogenic acute stroke is much rarer, with an estimated prevalence of five cases out of 100,000. However, unlike conditions such as psychogenic movement disorders, psychogenic stroke mimics present a unique challenge because of the acuity in which a treatment decision needs to be made, and because of the high stakes associated with making the wrong decision.³

While the risks of treating stroke mimics with tPA are very low, they are not zero. Treatment with tPA carries the risk of potentially fatal hemorrhage, both into the brain and at other sites of the body. Because of this risk, patients treated with tPA need to be admitted to a high level of clinical care such as an intensive care unit, where they can be monitored by nurses with subspecialty training in neurological disorders. Additionally, patients treated with tPA need to undergo advanced radiological imaging and other specialized diagnostic tests.⁴ Therefore, treatment with tPA requires hospitalization in a high-acuity setting and significant use of healthcare resources (see further discussion of this below). Although tPA administration has medical and financial implications, the consequences of withholding tPA from a patient who is having an ischemic event could be grievous.

In patients with suspected psychogenic stroke mimics, do the risks of potentially devastating clinical deficits from a missed stroke outweigh the risks of administering tPA? How should beneficence and nonmaleficence be balanced when making treatment decisions for these patients? Herein, we present two cases of patients with suspected psychogenic stroke mimics to illustrate the challenges physicians face in managing these scenarios.

CASE 1

A 47-year-old man presented to our hospital complaining of 30 minutes of left-sided weakness. He endorsed cocaine use the day prior to presentation. His National Institute of Health Stroke Scale (NIHSS)—a standardized measure of stroke severity—was 13 due to hemiplegia (complete inability to move the left side) and hemisensory loss (lack of sensation on the left side).⁵ However, his deficits were inconsistent: on direct examination, he appeared to be hemiplegic, but on passive observation, he was seen moving his left side. This raised the question of a psychogenic stroke mimic. Despite this, after obtaining a computed tomography (CT) scan of his brain, the decision was made to administer tPA, given that cocaine use is a risk factor for stroke and his NIHSS score was high. The following day,

he continued to report hemiplegia, but he was seen walking to the bathroom unattended. Magnetic resonance imaging (MRI) showed no infarct. He was discharged 48 hours later, with a plan for outpatient psychiatric referral and physical therapy.

CASE 2

A 70-year-old undomiciled man with recently diagnosed leukemia was admitted to the hospital for chemotherapy. Three weeks later, he was told that he would be discharged and chemotherapy would be continued as an outpatient. The following morning, he was found unresponsive. He did not open his eyes or react to sternal rub, suggesting that he was unconscious, but he forcefully resisted passive eyelid-opening, which an unconscious patient would be unable to do. When his arms were lifted, they drifted down, but never hit his face, suggesting that he was able to control them. Twenty minutes later, he was observed being assisted out of bed to urinate, but when he was led back to bed and formally examined, he became unresponsive again. Because of these inconsistencies in his presentation, his symptoms were felt to be psychogenic, and tPA was not offered. Nonetheless, a CT scan of his brain and a CT angiogram of the blood vessels in his head were obtained. The CT angiogram revealed that while there was no arterial blood clot, as one would expect to see in the traditional presentation of stroke, there was a sinus thrombosis—a blood clot in the deep veins of the brain, explaining his unusual presentation. Anticoagulation was started. An MRI showed acute infarction of the pons, midbrain, and thalami, and he died the following day. While this case turned out to be a venous clot, which is not treated with tPA, it demonstrates that symptoms that appear to be psychogenic can in fact be due to devastating neurological injury.

DISCUSSION

The Clinical Approach to Suspected Psychogenic Stroke Mimics

tPA is the standard of care for all patients presenting with symptoms compatible with acute ischemic stroke within four and one-half hours, provided there are no contraindications. In the best case scenario, patients become asymptomatic after receiving tPA and are able to be discharged home 24 to 48 hours later. More than one-third of patients treated with tPA are able to walk independently after discharge from the hospital.⁶ The earlier that tPA is given, the better the outcome.

The pressure to make tPA decisions quickly poses a challenge when there is clinical uncertainty about whether a patient's symptoms are due to stroke. There are limited data on psychogenic stroke mimics. This may be due to underreporting or mischaracterization of psychogenic stroke mimics as real strokes. Despite this, the most common mimics of stroke are known to be seizure, migraine, and psychogenic disorders. Seizures can masquerade as stroke because patients are often weak on one side of their body after a seizure. Similarly, some patients develop weakness on one side of their body before, during, or after migraines. As discussed in case 1 and detailed further below, patients may also have unilateral weakness due to a psychogenic etiology.⁷ Notably, the latest tPA administration guidelines from the American Heart Association do not view suspicion of a stroke mimic as an exclusion criterion for treatment because the complication rate associated with giving tPA to patients with stroke mimics is very low (less than 1 percent across two large cohort studies).⁸

The Ethical Approach to Suspected Psychogenic Stroke Mimics

Because the potential to cause harm by not giving tPA to a patient who is having a true stroke is so high and the potential of giving tPA to a patient with a psychogenic stroke mimic is so low, the ethical principle that should guide tPA administration is the principle of beneficence. This is illustrated in case 1, in which, given the patient's presentation and his vascular risk factor of recent cocaine use,

the potential benefits of giving tPA were thought to outweigh the risks, and the potential harm of not treating was felt to be greater than the potential risk of giving tPA. It can be challenging for physicians to convince themselves with 100 percent certainty that a patient who appears to have symptoms due to a psychogenic etiology is not having a real stroke. Patients who are having strokes may embellish their true neurological symptoms, making it difficult for careproviders to distinguish real symptoms from psychogenic symptoms. In addition, genuine stroke symptoms often fluctuate. While there are some helpful examination findings that support the conclusion that symptoms are psychogenic, these can often be misleading and falsely reassuring (see table 1).⁹ Because these findings are not 100 percent sensitive or specific for psychogenic stroke mimics, it could be maleficent to deny a patient with stroke symptoms tPA based on these findings. For example, in case 2, there were inconsistencies in the neurological examination that suggested that this was a psychogenic stroke mimic, but the patient ended up having a stroke. Although the stroke turned out to involve a venous clot that would not be treated with tPA, this presentation, which was presumed to be psychogenic, could just as easily have been that of a basilar clot, and the delay of tPA would have been devastating.

In some circumstances, however, it is clearly so unlikely that a patient's symptoms are due to a true stroke that a decision about tPA administration should be based not on the principle of beneficence, but rather on the principle of nonmaleficence. For

TABLE 1. Findings suggestive of psychogenic neurological symptoms

Finding	Comments
Inconsistencies on examination	<ol style="list-style-type: none"> 1. Presence of motor deficits that are seen only during formal observation, but abate in other circumstances 2. Complaint of a weak upper limb, but observation that when the limb is raised above the patient's face, it never falls and hits the face 3. A positive Hoover sign in which there is less pressure under the good leg than under the weak leg when asked to raise each leg separately 4. Fluctuation of sensory deficits that do not follow a clear neurologic distribution
No objective evidence of disease	<ol style="list-style-type: none"> 1. Normal neuro-imaging 2. Subjective weakness but full power on direct confrontation
Distractibility	<ol style="list-style-type: none"> 1. Complaint of hemiplegia despite ability to utilize the purportedly plegic limbs during conversation or portions of the examination not designed to focus on strength evaluation
La Belle Indifference	<ol style="list-style-type: none"> 1. Absence of concern about symptoms (caution, this can be confused with cortical deficits such as anosognosia or abulia)

example, if a young woman being treated for an asthma attack suddenly develops severe hemiparesis, it would be reasonable to consider acute stroke as a potential diagnosis. But if she experiences these symptoms a few times each month prior to developing a migraine, and says she is starting to develop her typical headache, then although stroke is a possible diagnosis, it is so unlikely that it would not be in her best interests to give her tPA. In this case, the potential risks of giving tPA outweigh the potential benefits, so offering treatment under the ethical construct of beneficence would run counter to the principle of nonmaleficence. In essence, there needs to be an ongoing assessment of proportionality, or analysis of benefit to burden, when making these acute decisions.

Diagnosis and Treatment of Patients with Known Psychogenic Stroke Mimics

When a patient presents with symptoms that are determined to be non-organic, it is still necessary to explore the etiology for their presentation. According to the American Psychiatric Association *Diagnostic and Statistical Manual of Mental Disorders*, there are three forms of psychogenic symptoms: malingering, factitious, and functional (conversion) disorders (see table 2).¹⁰ Clinicians should be aware that sexual abuse and physical abuse are risk factors for these disorders, and while it can be frustrating to manage patients with non-organic symptoms, it is important to treat them with compassion.

Both acute management and long-term management of patients who present with psychogenic stroke mimics are challenging. Reassuring a patient that a stroke did not occur, and providing a possible explanation for the cause of her or his symptoms in

an honest and nonconfrontational manner can be of therapeutic value. However, some psychiatrists believe therapy is of little benefit due to the nonchronic nature of pseudostroke. This is a controversial topic, and further research in the area is warranted.¹¹

As highlighted in case 1, patients with suspected psychogenic strokes are sometimes discharged to an inpatient rehabilitation facility for further treatment. It is important to note that although physical rehabilitation has been shown to be effective in some functional neurological disorders including functional motor symptoms,¹² it does not address the underlying pathology, adds additional costs, and may reinforce the belief that the symptoms have organic causes. The optimal management of psychogenic stroke is uncertain, and appropriate resources can be difficult to arrange, since in most communities mental health resources are scarce and underfunded. Ideally, outpatient psychiatric follow up should be arranged for these patients, but this can be challenging due to limited resources and long wait times.

Although the recurrence rate of psychogenic stroke is unknown, it is not zero. The patient in case 1 later presented to a sister hospital and again complained of hemiplegia and numbness. Because the neurology residents were familiar with him, they were careful to evaluate for discrepancies between exam findings and behavior when the patient did not know he was being observed. Based on prior experience with him and inconsistencies in his exam, the team confidently withheld tPA and attributed his symptoms to a psychiatric condition, most likely malingering or factitious disorder. In so doing, they prevented another hospital admission for a redundant stroke workup, thereby avoiding misallocation of resources and a high-acuity hospital

TABLE 2. Potential *DSM V* diagnoses of psychogenic neurological symptoms

Diagnosis	Features
Conversion disorder	<ol style="list-style-type: none"> 1. Motor or sensory deficits not explained by neurologic disease 2. No evidence of intentional production of deficits 3. Often associated with physical or emotional abuse or neglect
Factitious disorder	<ol style="list-style-type: none"> 1. Intentional feigning of symptoms or self-infliction of injury for primary gain (desire to be a patient) 2. Often associated with antisocial or borderline personality disorder
Malingering	<ol style="list-style-type: none"> 1. Intentional feigning of symptoms or self-infliction of injury for secondary gain (shelter, disability payments, medications, etc.) leading to a marked discrepancy between complaints and exam findings and poor cooperation with diagnostic testing 2. Often associated with antisocial personality disorder and/or history of prior lawsuits

Source: American Psychiatric Association, *Diagnostic and Statistical Manual of Mental Disorders*, 5th ed. (Arlington, Va.: APA, 2013).

bed to a patient with a psychogenic stroke mimic. Notably, the cost of a hospitalization after administration of tPA is high, and insurance companies often decline reimbursement for hospitalizations of patients who are found to have psychogenic syndromes, a stance that strikes us as unethical and discriminatory, but that is nonetheless a reality at present.¹³ Goyal and colleagues found that the median excess hospital cost associated with administration of tPA to patients with stroke mimics was \$5,401 per admission.¹⁴ While it would be a mistake to allow these economic considerations to play a significant role in a decision about providing acute treatment (even in terms of pure economic calculus, since the long-term cost of managing permanent disability from untreated stroke would vastly exceed \$5,401), they do add to the overall picture of potential harm caused by giving tPA to a stroke mimic.

But what if our patient had a small acute infarction on his second presentation? In this case, would the residents have been too focused on being nonmaleficent and failed to be beneficent? When physicians evaluate patients with known psychiatric disease, especially in the acute setting, do we treat them differently? Are we biased against thinking the patients have real pathology? It is important to be humble and acknowledge that clinicians are not flawless and can be fooled by someone who appears to have conversion disorder and ends up having organic pathology. The absence of vascular risk factors and young age do not preclude true stroke, and when acute stroke is in the differential diagnosis and a patient is in the window for tPA, the patient should be offered treatment. Identification of symptoms as psychogenic requires appropriate workup to exclude all organic diagnoses.

CONCLUSION

This article discusses the challenging quest to find the ethical balance between beneficence and nonmaleficence when making time-sensitive decisions about administration of tPA to patients with suspected psychogenic stroke mimics. In legal, ethical, and moral respects, it is much easier to justify a misdiagnosis of stroke if a patient has a psychogenic stroke mimic than *vice versa*.¹⁵ However, while the complication rate of tPA in stroke mimics is low, it is not zero, and administration of tPA comes with a price for both the patient and the healthcare system, even when there are no complications. Effective treatment of patients with psychogenic symptoms requires a prompt and thorough physical exam and appropriate workup, honest communication,

and reassurance. We suggest a need for increased emphasis in the training of physicians about identification of psychogenic stroke mimics, the etiologies for psychogenic stroke mimics, and treatment options for these patients.

MASKING

Details in the cases have been altered to protect the identities of patients and family members.

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Positive HIV Test Results from Deceased Organ Donors: Should We Disclose to Next of Kin?

Anne L. Dalle Ave and David M. Shaw

ABSTRACT

In the context of deceased organ donation, donors are routinely tested for HIV, to check for suitability for organ donation. This article examines whether a donor's HIV status should be disclosed to the donor's next of kin.

On the one hand, confidentiality requires that sensitive information not be disclosed, and a duty to respect confidentiality may persist after death. On the other hand, breaching confidentiality may benefit third parties at risk of having been infected by the organ donor, as it may permit them to be tested for HIV and seek treatment in case of positive results.

We conclude that the duty to warn third parties surpasses the duty to respect confidentiality. However, in order to minimize risks linked to the breach of confidentiality, information should be restrained to only concerned third parties, that is, those susceptible to having been infected by the donor.

INTRODUCTION

A test for HIV (human immunodeficiency virus) is one of the routine blood tests that are conducted

Anne L. Dalle Ave, MD, MS, is an Ethicist in the Ethics Unit of the University Hospital of Lausanne, Switzerland, and at the Institute for Biomedical Ethics, University Medical Center of Geneva, Switzerland. *Anne.Dalle-Ave@chuv.ch*

David M. Shaw, PhD, is a Senior Researcher at the Institute for Biomedical Ethics, University of Basel, Basel, Switzerland, and at the Care and Public Health Research Institute, Maastricht University, the Netherlands. *david.shaw@unibas.ch*

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on organ donors, in order to avoid the transmission of diseases to seronegative recipients. If the result of an HIV test is positive, organs from the donor are usually not transplanted. However, organ donation may be considered¹ when compatible HIV-positive recipients are available. In the United States, organ donation from HIV-positive organ donors recently became permitted, but initially only under a research protocol.²

But what else should be done in case of a positive HIV result? Do health professionals have a duty to disclose positive HIV results to relatives or partners who were at risk of infection when doing so would be a breach of medical confidentiality?

There is no consensus answer to this question in the literature. In the United Kingdom, for instance, the next of kin is informed about “the need for virology testing and that results may be discussed with them if a test result were found to be positive.”³

In the U.S., according to Slam and colleagues, the Public Health Service Guideline for Reducing Transmission of Human Immunodeficiency Virus (HIV), Hepatitis B Virus (HBV), and Hepatitis C Virus (HCV) through Solid Organ Transplantation “does not address the ethical question of whether next of kin should be notified of a positive test if they were previously unaware and the ‘donor’ never consented to that testing, nor to disclosure to family members.”⁴

Here, we analyze the ethics of disclosing a positive HIV result from a deceased organ donor to third parties who might have been infected by the donor.

ETHICAL ANALYSIS

Professional Confidentiality for the Living

Professional confidentiality is the obligation to keep silent “a secret of which he [the physician] has knowledge or of which he becomes aware within his professional role.”⁵ However, as stated by Ketels and colleagues, professional confidentiality is not absolute, and “other values, such as the health of others, may indeed take precedence in certain circumstances.”⁶ Such exceptions to professional confidentiality have different justifications; these include a state of necessity,⁷ a duty to warn,⁸ a “duty to protect imperiled third parties,”⁹ and a “duty to breach patient confidentiality to protect others.”¹⁰ All of these refer to the same concept, that is, the idea that duties to protect others sometimes trump confidentiality concerns.

Since the emergence of HIV in the 1980s, discussions about whether to breach professional confidentiality in order to protect third parties have generated animated debates, and legislation and recommendations vary among countries.

In the U.K., the General Medical Council (the organization that helps to protect patients and improve medical practice across the U.K.) has stated that “Personal information may, therefore, be disclosed in the public interest, without patient’s consent, and in exceptional cases where patients have withheld consent, if the benefits to an individual or to society of the disclosure outweigh both the public and the patient’s interest in keeping the information confidential,”¹¹ and that “you may disclose information to a known sexual contact of a patient with a sexually transmitted serious communicable disease if you have reason to think that they are at risk of infection and that the patient has not informed them and cannot be persuaded to do so.”¹²

Nonetheless, there is no legal *duty* to warn those possibly infected in the U.K., because of the common law rule that there is no legal duty to rescue.¹³

In the U.S., and in many other countries, medical confidentiality is protected under the law.¹⁴ To override such a norm, good reasons are necessary and negative effects must be minimized.¹⁵ In 2001, Wolf and Lo wrote that, concerning HIV, physicians may be allowed to breach medical confidentiality and to disclose a positive HIV test from one of their patients to a third party if it “will help prevent serious harm to an identifiable person,” “there is no other effective means of achieving the goal,” and “the breach of confidentiality is minimized.”¹⁶ Generally, it is required that the physician try to persuade the patient to disclose his or her HIV-posi-

tive status to persons whom he or she may have infected or with whom he or she still engages in risky behavior. However, if the patient agrees to disclose her or his positive HIV status, the physician has no way of checking whether the patient has disclosed the information. This means that any such claim must be trusted in the absence of any evidence to the contrary. Depending on the country, if the patient refuses to disclose the information, and, if it is permitted by law, the physician can disclose the positive HIV result to identified third parties who are at risk of infection.¹⁷ If it is not permitted by law, the physician can notify local public health authorities. Furthermore, Lehman and colleagues write, some U.S. states have “legislation that criminalizes potential HIV exposure.”¹⁸

In 2006, the *American Journal of Bioethics* devoted several essays to the question of whether one should breach medical confidentiality to protect third parties.¹⁹ Kipnis, acknowledging “the collision between medical confidentiality and the duty to protect imperiled third parties,” advocated in favor of “an unqualified confidentiality rule,” that is, a rule that “contemplates no exceptions.”²⁰ Interestingly, he argued that unqualified medical confidentiality “will allow the profession to discharge its collective responsibilities to patients and society,” as it will be the responsibility of patients and/or society to balance the need to protect others against the need to protect confidentiality.²¹ Other authors pointed out that other values, such as “do not harm”²² and the duty to protect patients against diseases,²³ may outweigh medical confidentiality.²⁴

HIV disclosure is particularly challenging because of the stigma that still surrounds the disease. As Radcliffe states, “As long as people with HIV face stigma and discrimination from those close to them, from healthcare professionals, and from society, many will find it difficult to disclose.”²⁵

Professional Confidentiality for the Deceased Organ Donor

Professional confidentiality may continue even after death in some countries.²⁶ For instance, in the U.K., medical records cannot be accessed until 100 years after a patient’s death, with some exceptions for research purposes subject to approval by the Public Records Office.²⁷ In the U.S., however, according to Smolensky, the family has “the ability to obtain sensitive information about a decedent’s medical conditions.”²⁸

While some authors may advocate that the deceased person can have no interests, as they have ceased to exist,²⁹ many others believe that some in-

terests can survive the death of a person,³⁰ including confidentiality, wills,³¹ and reputation,³² acknowledging that some interests may persist after death. For instance, most societies will respect the wishes of a person concerning the disposal of their body after death (incineration or burial). Furthermore, most societies spend a lot of time and institutional resources protecting the wishes of a person who is dead by distributing their assets and enforcing wills. Finally, in English law, the notion of “extended best interests” has been acknowledged in the context of organ donation.³³ Traditionally, a patient’s best interests (which is the test doctors used for decision making regarding incapacitated patients) only concern what was of medical benefit to them, but consideration of extended best interests enables treatment aimed not at benefiting the patient, but at facilitating organ donation after his or her death—and thus enables the pursuit of interests beyond the point of death.³⁴ Indeed, organ donation, although presenting no direct medical benefit for patients, may represent indirect benefits for patients, if the well-being of others (through organ donation) is important for organ donors.

The particular question of whether health professionals have a duty to disclose the positive HIV results of a deceased organ donor to relatives or partners who are at risk of infection, when doing so would be a breach of medical confidentiality, is unresolved. To answer this question, one has to determine whether the interests of a living person override those of a decedent,³⁵ such as the preservation of his or her reputation or legacy.

The U.S. Centers for Disease Control and Prevention (CDC) estimates that “of the 1.2 million people living with HIV in the United States, nearly one in seven (more than 168,000 individuals) do not know they are infected.”³⁶ It is thus very possible that a deceased donor might have been unaware of her or his positive status or had chosen not to disclose it to persons whom he or she might have infected.

To disclose the positive HIV status of a deceased organ donor to third party who is at risk of having been infected would breach medical confidentiality, but, on the other hand, would permit the third party to seek necessary testing, counseling, and treatment in case she or he tests HIV positive, and would permit better public health prevention.

In the case of a deceased organ donor, the risk of harm induced by breaching medical confidentiality is minimal, as the person is dead. Principally, breaching medical confidentiality can harm the reputation and memories of the deceased.³⁷ It will concern only

the “image” of the person after her or his death, but will not negatively affect her or his personal, professional, or spiritual relationships, as would be the case for a living person, as positive HIV status is still unfortunately surrounded by stigma. It can also harm persons who are related to the deceased, by interfering with their memories of the person, particularly as long as HIV has a connotation of stigma.

The benefits of breaching confidentiality are obvious for those who may have been infected with HIV: they can be tested for HIV, and if the results are positive they can seek treatment (to turn a lethal disease into a chronic condition), refrain from risky behaviors, and also inform any recent sexual contacts that they too might be infected. It can be argued that the duty to warn is more important than the duty to respect confidentiality—particularly after death. In countries where healthcare professionals can inform third parties of the risk of HIV transmission despite the fact that the patient wants his or her HIV status to be kept confidential,³⁸ it would be odd not to also inform people that a now-dead person who can no longer be harmed by the disclosure posed a risk of infection. Furthermore, one of the reasons for not informing sexual partners about the HIV-positive status of a living patient is the possibility that the patient will him- or herself disclose that information. This is obviously not an option for a deceased patient, and given the potential risk to the bereaved partner (and previous sexual partners), disclosure will often be appropriate. In one case in the U.K., the sister of a deceased patient informed staff that he had been HIV positive and his wife—and two young children—remained unaware of this. In this case a decision was made to disclose this information. Ultimately, the right to confidentiality of the deceased person must not be weighed only against the rights of his or her most recent sexual partner, but also against the prospective benefit and prevention of harm to previous sexual partners of the deceased and future (and perhaps also previous) sexual partners of the surviving sexual partner. In more complex cases involving multiple sexual partners who may have been infected, public health authorities tend to work with the police in tracing and contacting those at risk.

Overall, as the benefits of disclosure outweigh the risks of breaching medical confidentiality, health professionals have a duty to inform third parties who are at risk of infection. However, risks linked to the breaching of confidentiality should be minimized to avoid harm induced by such information. Thus, policies and consent procedures should indicate to potential donors how the positive HIV results of de-

ceased organ donors will be given to concerned third parties.

Generally, during the process of obtaining consent for organ donation by surrogates, the organ procurement organization (OPO) team informs donors' next of kin that blood tests, such as HIV test, will be conducted on their relative. The team also usually inquires if the deceased organ donor was known to suffer from particular diseases, such as hypertension, diabetes, and HIV, and if he or she had previous risky behaviors that might have led to infection with HIV. This is the perfect moment to consider not only the organ recipient's future health, but also the well-being of third parties who are at risk of having been infected, and public health more generally. For instance, next of kin can be informed that HIV tests will be performed and that positive results would be returned only to third parties at risk of having been infected, specifying that the goal is to permit the concerned person to be tested and to prevent further spread of the disease, while still minimizing the breach of medical confidentiality. Names and contact information of known third parties who would be at risk of infection could be obtained during the discussion with the family, so that these persons would be easily contacted in case of a positive HIV result. However, it is possible that family members would not have such information, and such discussions would need to be cautious, as questions regarding sexual partners or drug use may be delicate to raise. If the medical team already knows the positive HIV status of the deceased organ donor (because the information is available from the medical chart, for instance), and still considers him or her as a potential organ donor, a similar procedure (see above) can be used, as confirmation of positive HIV status will be necessary, in addition to further laboratory tests such as CD4 count and viral load.

Such a procedure will mean that in case of positive results, only persons who might have been infected by HIV would be directly informed of positive tests. This would protect sensitive information from being spread among persons who could not benefit from it, such as parents or siblings of the deceased person.

Usually, if organ donation cannot go ahead, the reasons are explained to the family (for instance, tests discover an active oncologic disease). In cases when organ donation cannot be pursued because of a positive HIV test result (if, for example, no HIV-positive recipients exist), the reason should be disclosed only to a concerned third party and not to other family members, in order to protect and respect medical confidentiality.

CONCLUSION

Under specific conditions, health professionals working in transplant coordination have a duty to inform concerned third parties about a positive HIV test from a deceased organ donor. However, in order to minimize risks of stigmatization and harm, an adequate procedure that will inform only the concerned third parties has to be in place. Here we have considered the issue of HIV status, but similar parallels could be drawn with hepatitis B and C, or with any other transmissible disease. A detailed analysis of other infectious diseases is outside the scope of this article. Briefly, one may argue that because such diseases carry less stigma than HIV, and one might thus expect less harm to the deceased's reputation and image, it might be argued that the threshold for disclosure should be lower.

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Posthumous HIV Disclosure and Relational Rupture

Laura K. Guidry-Grimes and D. Micah Hester

ABSTRACT

In response to Anne L. Dalle Ave and David M. Shaw, we agree with their general argument but emphasize a moral risk of HIV disclosure in deceased donation cases: the risk of relational rupture. Because of the importance that close relationships have to our sense of self and our life plans, this kind of rupture can have long-ranging implications for surviving loved ones. Moreover, the now-deceased individual cannot participate in any relational mending. Our analysis reveals the hefty moral costs that disclosure can bring, which should influence what information is given to would-be donors and how organ procurement coordinators approach these conversations.

We generally agree with the ethical argument put forward by Anne L. Dalle Ave and David M. Shaw in their article, “Positive HIV Tests from De-

ceased Organ Donors: Should We Disclose to Next of Kin?” concerning HIV disclosure in deceased donation cases.¹ However, because the authors inadequately account for how procurements actually happen in specific cases, we believe that they have not sufficiently acknowledged an important moral risk in these disclosures. Specifically, the authors suggest that such disclosures “will concern only the ‘image’ of the person after his/her death, but will not negatively affect her/his personal, professional or spiritual relationships.” We disagree and argue, instead, that these disclosures can, at least in some cases, cause deep relational ruptures between the now-deceased individual and some of those who survive her or him. This rupture, we will argue, has significant implications for how survivors view the identities and life plans they built around that relationship, especially since the deceased individual is incapable of participating in any relational mending.

In this commentary, we will provide a brief overview of the process of disclosing a positive test for human immunodeficiency virus (HIV) in a deceased potential organ donor and highlight some ethical issues that can arise in carrying out the details of this process. In order to ground our discussion in the reality of how organ procurement actually occurs, we will base our discussion on procurement processes in our home state of Arkansas, although many of these details will be shared by other states as well.

Laura K. Guidry-Grimes, PhD, is an Assistant Professor of Medical Humanities and Bioethics at the University of Arkansas for Medical Sciences (UAMS) in Little Rock, Arkansas, and she is a Clinical Ethicist at UAMS and Arkansas Children’s Hospital. LGuidryGrimes@uams.edu

D. Micah Hester, PhD, is Chair of the Department of Medical Humanities and Bioethics and Professor of Medical Humanities and Pediatrics at the University of Arkansas for Medical Sciences (UAMS) in Little Rock, Arkansas, and he serves as a Clinical Ethicist at UAMS and Arkansas Children’s Hospital.

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While the authors focus on disclosure in relation to warning at-risk individuals, we broaden our analysis to include disclosures that routinely occur for the purpose of informing next of kin or an agent why an authorized donation will not proceed.² We will then focus our attention on the moral risk of relational rupture. Our analysis illustrates the hefty moral costs that these disclosures can bring, which should affect what information is given to would-be donors and how organ procurement coordinators approach this task.

THE PRACTICE AND MICRO-ETHICS OF DISCLOSURE

Depending on circumstances, different individuals may be responsible for disclosure of HIV status, and the nature of the disclosure conversation will depend on the role of the one disclosing. Treating physicians do not routinely screen for HIV, and if a patient is screened, physicians (should) only disclose HIV status (absent any specific laws or other duties of disclosure to state agencies or individuals) to another party (1) when the patient is incapacitated, (2) the party is identified as the surrogate decision maker, and (3) the HIV status is pertinent to healthcare decisions that have to be made for the patient. In the context of our state, when a patient dies and has been designated as a potential organ donor, the organ procurement organization (OPO) takes over the primary role in coordinating next steps. The coordinator for the OPO approaches the legally appropriate person (usually the next of kin or agent, who may not be the surrogate for other healthcare decisions) and describes the tests that are run, what would keep the OPO from procuring organs, and mandatory reporting requirements to public health agencies. While the coordinator may not ask for consent to procure, she or he has this conversation with the next of kin/agent (NOK/A), even if the patient designated him- or herself as a donor.

Unless the OPO works with a hospital that accepts HIV-positive organs under the HIV Organ Policy Equity (HOPE) Act,³ if the OPO's initial screening is reactive for HIV, then the OPO will not procure the organs. OPOs vary in how they handle this revelation with the NOK/A, either disclosing at that time or waiting until the OPO has run confirmatory tests, which can take two weeks to complete. In our state, the organ procurement coordinator would work with the OPO's medical director to craft a letter that is sent to the NOK/A, describing the results of the tests in more detail. While the coordinator or the letter can encourage the NOK/A to in-

form any at-risk individuals, the OPO is only permitted to disclose to the NOK/A. In Arkansas, the OPO is required to report positive HIV results to the Arkansas Department of Health, and this agency then takes steps to assess and manage infection risks. It is, therefore, the Arkansas Department of Health that has the legal authority and responsibility to disclose to at-risk individuals.

The micro-ethics of the conversations between the OPO and NOK/A include considerations of transparency, trust, role delineation, empathic communication, showing respect for the deceased individual and surviving loved ones, and providing on-the-spot education in a sensitive and helpful manner. Thoughtful judgment calls must be made to determine how best to separate the NOK/A from others at the bedside and how to emphasize the implications of serology testing. For instance, the family might not have read or understood the part of the authorization form that describes testing, so they might not have grasped the full implications of having the deceased tested for certain infectious diseases, some of which are stigmatized. Given this, OPOs should decide how its staff should respond to a preliminary positive HIV result while evaluating a deceased patient; it is not morally neutral whether to disclose the preliminary results immediately to the NOK/A or to wait for confirmatory tests. If the OPO chooses to disclose in the moment, then staff must be prepared to give useful information about risk factors and allay misinformed fears, which can be especially challenging given common misunderstandings about this disease. If the OPO chooses to wait, the coordinators need a way of responding to the family's questions respectfully and honestly. The letter that the OPO medical director writes to the NOK/A could perhaps allow for individualized recommendations, information about risk factors, and suggestions for whom to contact. This letter could be one of the last documents that a loved one receives about the recently deceased, and the care exhibited in the letter could make a significant difference for how the individual processes those final hours in the hospital. Having these details in the form of a letter has its own drawbacks, since person-to-person contact might be preferable for many loved ones in this situation, so they can ask additional questions, talk through available resources, and have the human connection from the beginning to the end of this process.

These micro-ethical concerns can be further enumerated; however, we choose to devote the balance of our comment to an aspect of the HIV disclosure process that should not be overlooked: the poten-

tial for relational rupture with long-ranging consequences for surviving loved ones.

RELATIONAL RUPTURES, POSTHUMOUSLY

Intimate relationships substantially influence how we develop our sense of self over time. David DeGrazia nicely makes this point:

A large part of who you are is a function of your interpersonal relationships, some of which are central to your identity. . . . So, to some extent, their interests are your interests. That is why if my wife or daughter flourishes, I am *ipso facto* better off. It is not simply that their flourishing makes them better company, or easier to live with or care for. To the extent that they are part of my identity, our interests overlap and their well-being constitutes part of my well-being.⁴

We are relational creatures, relying on others to develop and maintain our sense of self over time. Our relationships also transform how we structure our ends—that is, how we make plans and set personal aims. Connection with another person could make us more likely to take certain risks or embrace new endeavors. An individual's interests—be it Indian cooking, reading historical biographies, or wakeboarding—could all trace back to sharing time with another person and having the affection they share and those experiences shape who they are.

Imagine that Jane had been married to George for 20 years before he died suddenly, and after authorizing his organs for donation, Jane learns from the OPO that George was HIV positive. Before this revelation, Jane thought of herself as, among other things, a partner to an honest man who shared every major aspect of their lives together. She took a certain amount of pride from knowing George better than anyone. Upon hearing that he had HIV, she might start to doubt the closeness of their relationship and how she has built her sense of self over the last 20 years. She allowed herself to be changed by the relationship, but now there is potential evidence that George was not equally vulnerable with her. She might never know whether he knowingly put her risk. Processing her grief over his death has just become all the more confounding and difficult. Their shared interests will continue to guide Jane's life after his death, at least initially, because of the pull that our close relationships have on our identity. In this way, their relationship continues in some form for Jane, but Jane does not have the benefit of critically reflecting on any of this *with* George. As such, the relationship might always feel ruptured to her, even

if she copes with the revelation and its uncertainties at some point. Jane might wonder whether she made a mistake in authorizing the organ donation, given how it led to new tests and disclosures. Especially if her own tests happen to be negative, she might think that she would have been better off, in the end, if she had decided against donation. At minimum, she might wish that she had been more informed of this particular risk of world-altering disclosure.

Roles such as “spouse” or “sibling,” “friend” or “colleague” are not simply accidental attributes in our lives. They make up a substantive part of who we *are*. Information, actions, choices, and events have the power to undermine, fundamentally, the status of those relationships and, in turn, our very sense of self. As such, disclosure of something as nontrivial as HIV can impact relationships, and thereby, make us question who we are. It would seem, then, that limiting disclosure is good practice. However, the distribution of disclosure is not under the control of healthcare professionals alone. In fact, the NOK/A is entrusted with much of the information and decision making in the procurement process. The NOK/A could inform others, and any at-risk individuals could be contacted by a public health agency. Additionally, if anyone learns that the organ procurement was planned but then suddenly canceled, they might end up inferring the patient's HIV status. Given that disclosure is difficult to delimit, we must acknowledge that there is a reasonable chance that many people can come to know the HIV status of the deceased, and such a discovery could affect how survivors view their relationship to the deceased, which has further implications for how survivors view the parts of themselves and their lives that were structured around that relationship.

Dalle Ave and Shaw mention that HIV is shrouded in stigma and unfair bias, and this is not unimportant, but the authors focus too narrowly on these concerns. We contend, more broadly, that the revelation of HIV could impact relationships for other reasons as well. At-risk individuals are left with a number of upsetting questions: What is the level of risk they now have? Did the deceased knowingly put them at risk? Have they now unknowingly put others at risk as well?

Additionally, close relationships are built on each person's willingness to be vulnerable and to confide in one another. Although few, if any, relationships demand *total* disclosure of *all* sensitive information and *complete* vulnerability, true intimacy (in the sense described here) involves mutual

trust in being charitable, kind, and supportive of each other, even when those dispositions are normally difficult with other people or in trying circumstances. If one person does not share an important aspect of her or his life, something central to that person's health and relationships and overall well-being, then the other person might reasonably doubt to what extent their relationship is/was close at all. A brother, for example, might feel deeply hurt that his sister did not trust him with her HIV status, and he might feel that they lost out on opportunities for bonding and support. A caring and distraught loved one might think, "I would have been there for her. Why couldn't she trust me with this?" None of these considerations are unique to HIV; there could be similar impacts on relationships if it were discovered that an individual chose not to reveal his or her heart attack history, hepatitis A, or (beyond issues of disease) the existence of an estranged spouse. However, the life-threatening nature of HIV, if unmanaged, and the stigma surrounding it make its disclosure especially sensitive.

Of course, there are numerous factors that could excuse or at least partly justify the withholding of HIV status. The individual might not have known; he or she could have learned recently and wanted to process the news on his or her own first; the individual might have believed he or she should withhold out of consideration for what was happening in the other person's life; or maybe the individual was wary of how the relationship might be transformed by the disclosure, and holding onto normalcy was more valuable at the time. The individual might have also had legitimate concerns that the relationship was *not* as close as the other person believed, for example because the other person revealed harsh judgmental attitudes towards people with HIV in the past. When this revelation occurs while both people in the relationship are alive, there is a *possibility* of discussion, explanation, apology (if called for), and support. They have a chance, at least, to move forward in their relationship and build new closeness around this aspect of the persons' life, particularly since living with HIV, following a medical regimen, and enduring through stigma can be challenging for many individuals. The other person has the opportunity to prove her- or himself, so to speak, as a trustworthy and loving family member or friend. When the disclosure of HIV occurs posthumously, then all of these possibilities end; the now-deceased individual cannot respond to the aftereffects. Even if the individual had the foresight to leave a letter before dying to address some of foreseeable questions, a letter cannot take the place of interpersonal interac-

tions in which both people have the ability to ask questions, listen empathically, ask for apologies (again, if called for), and decide together how to move forward in their relationship.

CONCLUSIONS

The authors offer an ethical analysis that touches on a number of salient concerns in cases of deceased donors with positive HIV status. The authors say that damage to the reputation or image of the deceased is the only harm at stake, but we contend that there is a significant moral risk of what we are calling "relational rupture." One response to this concern is to increase public awareness of the routine tests done as part of the donation process as well as any reporting requirements, so would-be donors can evaluate this risk for themselves and plan accordingly. The authors make a similar suggestion, and we have elaborated on the reasons why this educational effort could help alleviate relational harms. For example, in a hospital participating in the HOPE Act, an informed HIV-positive patient could choose to designate a trusted person as her or his agent for organ donation decisions, and the patient could tell the agent what sort of narrative or context the patient wants to accompany disclosures. An individual who wished to minimize disclosure of his or her HIV status might choose against donation.

Our argument also has implications for how organ procurement coordinators should approach conversations with the NOK/A. Coordinators should take steps to ensure that the information about serology testing and reporting requirements is sufficiently understood. Family members might not have considered that the now-deceased individual was at risk for HIV, so this information could slip by if not accentuated by the coordinator. While assessing family members' level of understanding, the coordinator should also make the point that the information gleaned from these tests can be extremely difficult for loved ones to process, particularly since they do not have the benefit of discussing any positive results with the now-deceased individual. This conversation will require great care and tact, and it should be part of every organ authorization discussion, since these revelations can occur in any family.

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Kimbrough provided the invaluable perspective of an attending physician working in a surgical intensive care unit. We also thank Jake Earl and Jamie Carlin Watson for talking through early ideas and drafts.

NOTES

1. A.L. Dalle Ave and D.M. Shaw, "Positive HIV Test Results from Deceased Organ Donors: Should We Disclose to Next of Kin?" in this issue of *JCE*, volume 29, number 3 (Fall 2018).

2. The authors do mention that the reason for not pursuing organ donation due to positive HIV status "should be disclosed only to a concerned third party and not to other family members," but it is not clear who they think would qualify as a "concerned third party" for this purpose or how this claim fits in their weighing of duties to warn and to respect confidentiality.

3. UNOS, "At Two Years, HOPE Act Still Offering Hope." 1 December 2017, <https://unos.org/at-two-years-hope-act-still-offering-hope>.

4. D. DeGrazia, *Human Identity and Bioethics* (New York, N.Y.: Cambridge University Press, 2005), 87.

Plain Anabaptists and Healthcare Ethics

James Benedict

ABSTRACT

Plain Anabaptists are a small but rapidly growing ethnoreligious society with significant concentrations of population in a number of regions in North America. Among the most widely known of the various groups of Plain Anabaptists are the Amish and the Old Order Mennonites. It is the purpose of this article to provide insight into the culture and values of the Plain Anabaptists so that those who may be called upon to address ethical conflict involving Plain Anabaptists can do so with appropriate knowledge and sensitivity. The discussion of the culture and values of the Plain Anabaptists will be organized as follows: first we will explore the implications of Plain Anabaptist culture and values for applying the ethical principles of respect for autonomy and beneficence/nonmaleficence. Second, a brief description of several elements of Plain Anabaptist culture will be discussed with attention to the potential they create for ethical conflict in the healthcare setting.

INTRODUCTION

Plain Anabaptists are a small but rapidly growing ethnoreligious society with significant concentrations of population in a number of regions in North America. Among the most widely known of the various groups of Plain Anabaptists are the

Amish and the Old Order Mennonites. Other lesser known groups include German Baptist Brethren, Hutterites, members of Bruderhof communities, and Apostolic Christian Churches.¹ While Plain Anabaptist communities exist from Alaska to Florida, and from California to Maine, the greatest concentrations are found southern Pennsylvania, northeast Ohio, northern Indiana, southern Manitoba, and southern Alberta.²

Often recognizable by their plain, rustic looking clothing, prescribed hairstyles (including facial hair for men), modest dress, and head coverings for females, Plain Anabaptists embrace many values that are countercultural. These values are expressed in lifestyles that reject certain forms of modern technology in order to promote or preserve community cohesion. Plain Anabaptists do avail themselves of modern healthcare, but their values and commitments impact the manner in which they do so, with the result that they are sometimes misunderstood or considered “difficult” patients.³ On rare occasions, the differences between Plain Anabaptist values and the typical values encountered in North American healthcare may result in situations of ethical conflict.

It is the purpose of this article to provide insight into the culture and values of the Plain Anabaptists so that those who may be called upon to address ethical conflict involving Plain Anabaptists can do so with appropriate knowledge and sensitiv-

ity. The discussion of the culture and values of the Plain Anabaptists as they apply to interaction with healthcare professionals and systems will be organized as follows: first, this essay will explore some of the implications of Plain Anabaptist culture and values for the application of the ethical principles of respect for autonomy and beneficence/nonmaleficence. Second, a brief description of several elements of Plain Anabaptist culture will be discussed with attention to the potential they create for ethical conflict in the healthcare setting.

AUTONOMY

The attitude of Plain Anabaptists toward the value of autonomy can appear paradoxical to outsiders. On the one hand, Plain Anabaptists insist upon autonomous decision making with regard to anyone joining the religious community, including those who may have been born and brought up as part of a Plain Anabaptist family. One becomes a member only when one is of sufficient age and capacity to decide for one's self to do so. This decision and the community's acceptance of a new member are ritually enacted in baptism, typically in the late teens or early adulthood.⁴

Yet this autonomous decision to become part of the faith community is, in part, a renunciation of the priority of the individual, a willing surrender of one's self to God and the community. For Plain Anabaptists, the decision to become a part of the faith community includes the embrace of a way of life emphasizing community cohesion and *gelassenheit*, a term that describes submission to higher authority, that is, God, the elders within the community, and the community itself.⁵ Deference to authorities within their community and a tendency to place a higher value on community well-being than on individual well-being sometimes raises a suspicion among healthcare providers that patients' autonomy is being suppressed.⁶

If asked, adult patients with decision-making capacity will typically affirm that deference to authority and adherence to the values of the community are in fact their choice. However, when patients no longer possess decision-making capacity, or when they have never possessed it (as in the case of children and some with mental defect), the discomfort of healthcare providers may be heightened. On the whole, it is reasonable to assume that if the patient who no longer possesses decision-making capacity was a long-term member of a particular Plain Anabaptist community, then his or her preference would have been to continue to follow the practices of the

community with regard to decision making. To put it in the language of contemporary healthcare ethics, "substituted judgment" would support respect for the decisions of surrogate decision makers even when those decisions may seem opposed to what might ordinarily be considered the patient's best interests.⁷

When children or other never-competent persons are involved, however, the substituted judgment standard is not applicable. In consequence, decision making for this class of Plain Anabaptist patients has a high potential for generating ethical conflict. Such conflicts can become more complex because of state and federal laws designed to protect such patients. Plain Anabaptists naturally desire the right to make healthcare decisions for their loved ones in keeping with their own ordering of values, but inasmuch as these values diverge significantly from modern, individualistic neoliberal values, healthcare providers seeking to provide culturally sensitive care may find themselves caught in the middle.⁸ Ethics consultation or deliberation in such cases must wrestle with the question of how to balance respect for a minority culture against the specific individual interests of a vulnerable patient.

The willingness of members of Plain Anabaptist communities to defer to authority within their faith community and to prioritize community well-being over individual well-being qualifies their attitude toward autonomy, but it should not be understood as a disinterest in or desire to avoid informed decision-making. Plain Anabaptists are keenly aware that outsiders do not share their values, and they do not wish to have decisions made for them by those who are not members of their communities. They do want ample information on their condition, prognosis, and options, including burdens and benefits, so that they, together with trusted others in their group, can make responsible decisions in keeping with community values.⁹

BENEFICENCE/NONMALEFICENCE

The principles of beneficence and nonmaleficence call upon those providing healthcare to pay close attention to the total well-being of the patient. Cultural competency in the application of healthcare ethics requires sensitivity to the ways individuals from diverse cultures may construct their definitions of well-being. What may constitute a benefit or harm from a standard medical point of view may not be perceived as such from the point of view of a particular culture. Further, the extent or weighting of a benefit or harm can be very different.¹⁰

For Plain Anabaptists, their firm commitments to their communities and the values of those communities affect their perceptions of burden and benefit. For those whose communities prohibit the ownership of automobiles, even travel to and from appointments can constitute a much larger burden than it does for others. For that reason, some practitioners familiar with Plain Anabaptists try to schedule as many services as possible in a single visit rather than requiring the patient to return later or go elsewhere for labs or imaging.¹¹ For those Plain Anabaptists whose communities forbid the use of electricity in their homes, any home care that depends upon electricity (for example, ventilator or home dialysis) is obviously problematic.¹²

Another important cultural value and practice that can have a major impact on the weighting of burdens and benefits among Plain Anabaptists is the avoidance of commercial insurance and unwillingness to accept government benefits.¹³ As more Plain Anabaptists begin to work for employers outside their faith group, a small percentage have obtained health insurance through work.¹⁴ Yet the vast majority still pays out-of-pocket for their care. In extreme circumstances, assistance may be sought or offered from the faith community, through freewill collections or gifts. Even then, however, there is a much keener awareness of the actual cost than is typical among the average healthcare consumer, so Plain Anabaptists tend to be resistant to expensive treatments.¹⁵

Of course, patients who are not Plain Anabaptists may also find travel to and from appointments burdensome, may find it difficult to deal with home care requirements, and may resist recommended treatment. What is important to remember about Plain Anabaptists, however, is that their reasons for resisting or rejecting recommendations as too burdensome are often grounded in their religious beliefs and values.¹⁶ As such, they should be afforded respect similar to that given religion-based care refusal by others, for example, refusal of blood transfusion by Jehovah's Witnesses.¹⁷

ELEMENTS OF PLAIN ANABAPTIST CULTURE

Ethical conflict in healthcare sometimes results less from fundamental differences in the interpretation of ethical principles than from simple misunderstandings that may be based in cultural differences. Multiple sources can be recommended for those who have the time and inclination to pursue a deeper understanding of Plain Anabaptist culture,¹⁸ but even some very basic knowledge of key elements

of Plain Anabaptist culture may be helpful in resolving or avoiding ethical conflict. What follows is a brief review of elements of Plain Anabaptist culture which may lead to misunderstanding.

Education and Language

While most Plain Anabaptist adults are intelligent and fluent in English, many have received an education only through eighth grade¹⁹ and speak English as a second language. They are generally able and willing to read health-related information that is accessible to them and may have significant insight into their medical condition on that basis. Providing them with written information is often helpful and welcomed, especially material that may be available online and can be printed out for them. As for language, there are two important language-related concerns. First, some young children among the Plain Anabaptists may not learn English until they begin school and thus require an interpreter.²⁰ Second, while generally fluent, adults among the Plain Anabaptists may not be familiar with certain colloquialisms, medical terms, or the description of emotions in English.²¹

Use of Complementary and Alternative Medicine

There is an unusually high rate of use Complementary and Alternative Medicine (CAM) among Plain Anabaptists, with 80 percent or more in some studies reporting the use of supplements, herbs, patent medicines, reflexology, and/or faith healing.²² Recourse to physicians and hospitals is typically undertaken only when it is obvious that alternatives are insufficient for the need, and often after "natural remedies" were attempted.²³ Both cost of care and belief in efficacy drive the use of CAM among Plain Anabaptists. Their attitude toward modern medicine tends to be quite pragmatic, and they do not automatically accord modern medicine or its practitioners high status or authority.²⁴ As part of the effort to prevent conflict and provide optimal care, it is important both to ask Plain Anabaptists about their use of CAM and to avoid showing disrespect for the practice.

Hierarchical Culture

Plain Anabaptist communities are hierarchical, with the bishops or elders at the top of the hierarchy.²⁵ Attempts to work around or undermine the authority of bishops or elders are likely to lead to further conflict, while efforts to include the bishop or elders may be valuable in resolving conflict. Certainly any outreach to the larger Plain Anabaptist community should include the clergy early in the

process, as lay members will look to their clergy for guidance on whether or not to get involved.²⁶ Plain Anabaptist clergy do not dress distinctively or self-identify by title, so it is often necessary to ask if a minister is present or how to contact an elder or bishop in order to include them in decision making if needed.²⁷ In certain circumstances, however, Plain Anabaptist patients do not wish to involve the church or bishop, and should be afforded the same degree of privacy and confidentiality as any other patient.

Expression of Emotion

Practitioners who work regularly with Plain Anabaptist populations often report atypical affect.²⁸ This is derived in part from a stoicism grounded in the belief that it is important to accept the “will of God,” whatever it may be. Another contributing factor may be discomfort with displaying strong emotions in the presence of outsiders.²⁹ Failure to display strong emotion in a context where it might be expected, for example, the death of a child, should not be read as indifference or as a sign of acute psychiatric disturbance.³⁰ In such circumstances, words of support and simple acts of kindness are appropriate and will be appreciated.

CONCLUSION

As a relatively small but rapidly growing population in North America, Plain Anabaptists present special challenges for healthcare providers and institutions. Because they are an ethnoreligious society with values that diverge significantly from the mainstream, there is a need for cultural competence to provide the best care to Plain Anabaptists and to avoid or resolve ethical conflicts. Ethics consultants and committees in areas with concentrations of Plain Anabaptists will find it helpful to develop some awareness of the culture and values of these religious communities. This brief essay is an attempt to provide a basic introduction.

NOTES

1. For a thorough description of the nature and varieties of Plain Anabaptists, see C. Anderson, “Who Are the Plain Anabaptists? What Are the Plain Anabaptists?” *Journal of Amish and Plain Anabaptist Studies* 1, no. 1 (April 2013): 26-71.

2. C. Anderson and Joseph F. Donnermeyer, “Where Are the Plain Anabaptists?” *Journal of Amish and Plain Anabaptist Studies* 1, no. 1 (April 2013): 1-25, 20.

3. D. Garrett-Wright et al., “Anabaptist Community Member’s Perceptions and Preferences Related to Health-

care,” *Journal of Amish and Plain Anabaptist Studies* 4, no. 2 (2016): 193-6; J.A. Cates, *Serving the Amish: A Cultural Guide for Professionals* (Baltimore, Md.: Johns Hopkins University Press, 2014), *passim*; M.J. Banks and R.J. Benchot, “Unique Aspects of Nursing Care for Amish Children,” *MCN* 26, no. 4 (2001): 194-5; J.A. Brewer and N.M. Bonalumi, “Cultural Diversity in the Emergency Department: Health care beliefs and practices among the Pennsylvania Amish,” *Journal of Emergency Nursing* 21, no. 6 (1995): 495-7; L.L. Graham and J.A. Cates, “Health Care and Sequestered Cultures: A Perspective from the Old Order Amish,” *Journal of Multicultural Nursing and Health* 12, no. 3 (2006): 62-5; A.F.Z. Wenger, “Culture-Specific Care and the Old Order Amish,” *National League for Nursing* 38, no. 2 (April-May 1991): 80-2, 84, 87; P.A. Sharpnack, M.T. Griggin, A.M. Benders, and J.J. Fitzpatrick, “Spiritual and Alternative Healthcare Practices of the Amish,” *Holistic Nursing Practice* 24, no. 2 (March-April 2010): 64-72, doi: 10.1097/HNP.0b013e3181d39ade.

4. D.B. Kraybill, *The Riddle of Amish Culture* (Baltimore, Md.: Johns Hopkins University Press, 1989), 99-100.

5. Not all Plain Anabaptists use the term *gelassenheit*, but the values implicit within the concept are common in every group. For a thorough treatment of *gelassenheit* and its importance as a key to understanding Plain Anabaptist culture, see Kraybill, *The Riddle of Amish Culture*, see note 4 above, pp. 24-31. For a description of the Plain Anabaptist understanding of the locus of moral authority, see D.B. Kraybill and C.D. Bowman, *On the Backroad to Heaven* (Baltimore, Md.: Johns Hopkins University Press, 2001), 262-5.

6. J. Kotva, *The Anabaptist Tradition: Religious Beliefs and Healthcare Decisions*, Religious Beliefs and Healthcare Decisions Handbook Series (Chicago, Ill.: Park Ridge Center for the Study of Faith, Health and Ethics, 2002), 4-5.

7. For a description of the substituted judgment standard, see T.L. Beauchamp and J.F. Childress, *Principles of Biomedical Ethics*, 6th ed. (New York: Oxford University Press, 2009), 136-7.

8. An excellent example of the “bind” in which healthcare providers may find themselves is the case study and multiple case analyses in A.H. Matheny Antommara et al., “Two Infants, Same Prognosis, Different Parental Preferences,” *Pediatrics* 135, no. 5 (May 2015): 918-23.

9. Garrett-Wright et al., “Anabaptist Community Member’s Perceptions and Preferences,” see note 3 above, p. 195; Kotva, *The Anabaptist Tradition*, see note 6 above, p. 4; Cates, *Serving the Amish*, see note 3 above, pp. 37-3; 137. It should be noted that Plain Anabaptists may choose to express their decisions in the form of advance directives. Cates, *Serving the Amish*, see note 3 above, p. 161.

10. Robert Veatch has argued that healthcare providers should only describe options, not make recommendations, because they have no way of really knowing how the patient values various burdens, risks, or benefits. Veatch is making this point for individuals, not cultural differences, but the general argument is similar. See R. Veatch, *Patient, Heal Thyself: How the New Medicine Puts*

the Patient in Charge (New York: Oxford University Press, 2008).

11. Beachy Amish and some Old Order Mennonites use automobiles, as do some German Baptist Brethren. Graham and Cates, "Health Care and Sequestered Cultures," see note 3 above, pp. 61, 63.

12. Plain Anabaptists generally do not prohibit the use of cars, although most prohibit ownership; most of those who do prohibit ownership will hire drivers with cars, vans, or trucks when necessary, for example, to travel a long distance. Likewise, not all prohibit electricity in the home, and some who do manage to have access to electricity to earn their living through the use of gas-powered generators.

13. As Garrett-Wright et al. explain, "Health insurance and government funding are viewed as a threat to their separation from the world and threatening to their practice of mutual aid." Garrett-Wright et al., "Anabaptist Community Member's Perceptions and Preferences," see note 3 above, p. 189

14. Graham and Cates, "Health Care and Sequestered Cultures," see note 3 above, p. 64; Banks and Benchot, "Unique Aspects of Nursing Care for Amish Children," see note 3 above, p. 193.

15. Wenger, "Culture-Specific Care and the Old Order Amish," see note 3 above, p. 82; Graham and Cates, "Health Care and Sequestered Cultures," see note 3 above, p. 62; Brewer and Bonalumi, "Cultural Diversity in the Emergency Department," see note 3 above, p. 495; Garrett-Wright et al., "Anabaptist Community Member's Perceptions and Preferences," see note 3 above, pp. 194-5; Sharpnack et al., "Spiritual and Alternative Healthcare Practices of the Amish," see note 3 above, p. 71; Cates, *Serving the Amish*, see note 18 above, p. 158.

16. Kraybill and Bowman, *On the Backroad to Heaven*, see note 5 above, p. 262.

17. For interesting discussions of dealing with treatment refusal by Jehovah's Witnesses, see I. Sagy, A. Jotkowitz, and L. Barski, "Reflections on Cultural Preferences and Internal Medicine: The Case of Jehovah's Witnesses and the Changing Thresholds of Blood Transfusions," *Journal of Religion and Health* 56 (2017): 732-8; and K.S. Naunheim, C.R. Bridges, and R.M. Sade, "Should a Jehovah's Witness Patient Who Faces Imminent Exsanguination Be Transfused?" *Annals of Thoracic Surgery* 92 (2011): 1559-64.

18. See Cates, *Serving the Amish*, see note 3 above; D. Garrett-Wright, M.S. Jones, and M.E. Main, "Anabaptist Community Members' Perceptions and Preferences Related to Healthcare," *Journal of Amish and Plain Anabaptists Studies* 4, no. 2 (2016): 187-200; and Kraybill and Bowman, *On the Backroad to Heaven*, see note 5 above. One may also contact the Young Center for Anabaptist and Pietist Studies at Elizabethtown College in Elizabethtown, Pennsylvania.

19. Graham and Cates, "Health Care and Sequestered Cultures," see note 3 above, p. 61.

20. Banks and Benchot, "Unique Aspects of Nursing Care for Amish Children," see note 3 above, p. 195; Cates, *Serving the Amish*, see note 3 above, p. 156.

21. Cates, *Serving the Amish*, see note 18 above, p. 160; Brewer and Bonalumi, "Cultural Diversity in the Emergency Department," see note 3 above, p. 496.

22. Banks and Benchot, "Unique Aspects of Nursing Care for Amish Children," see note 3 above, p. 194; Brewer and Bonalumi, "Cultural Diversity in the Emergency Department," see note 3 above, p. 495; Garrett-Wright, Jones, and Main, "Anabaptist Community Members' Perceptions and Preferences," see note 18 above, pp. 188-9.

23. Sharpnack et al., "Spiritual and Alternative Healthcare Practices of the Amish," see note 3 above, p. 68.

24. Cates, *Serving the Amish*, see note 18 above, p. 37.

25. *Ibid.*, 58; Banks and Benchot, "Unique Aspects of Nursing Care for Amish Children," see note 3 above, p. 194.

26. For example, endorsement of bishops for programs emphasizing farm safety or encouraging childhood immunizations are critical. Brewer and Bonalumi, "Cultural Diversity in the Emergency Department," see note 3 above, p. 496.

27. Cates, *Serving the Amish*, see note 18 above, pp. 40-2.

28. Graham and Cates, "Health Care and Sequestered Cultures," see note 3 above, p. 63.

29. Banks and Benchot, "Unique Aspects of Nursing Care for Amish Children," see note 3 above, pp. 195-6.

30. Brewer and Bonalumi, "Cultural Diversity in the Emergency Department," see note 3 above, p. 495.

Refusal of Vaccination: A Test to Balance Societal and Individual Interests

Kavita Shah Arora, Jane Morris, and Allan J. Jacobs

ABSTRACT

While all states in the United States require certain vaccinations for school attendance, all but three allow for religious exemptions to receiving such vaccinations, and 18 allow for exemptions on the basis of other deeply held personal beliefs. The rights of parents to raise children as they see fit may conflict with the duty of the government and society to protect the welfare of children. In the U.S., these conflicts have not been settled in a uniform and consistent manner. We apply a test that provides a concrete and formal rubric to evaluate such conflicts. For some vaccinations, based on the individual medical characteristics of the disease and the risks of being unvaccinated, the test would suggest that permitting conscientious exemptions is ethical. However, for vaccinations protecting against other diseases that are more severe or easily transmitted, the test would suggest that the federal government may ethically impose laws that deny such exemptions.

INTRODUCTION

Parental refusal to allow vaccination of their children (henceforth abridged as “vaccine refusal”)

Kavita Shah Arora, MD, MBE, is Director of Quality in the Department of Obstetrics and Gynecology, MetroHealth Medical Center; and is an Assistant Professor in the Department of Bioethics at Case Western Reserve University in Cleveland, Ohio. *Kavita.Shah.Arora@gmail.com*

Jane Morris, MD, is a Resident Physician in the Department of Obstetrics/Gynecology at MetroHealth Medical Center.

Allan J. Jacobs, MD, JD, is Chair of the Department of Obstetrics and Gynecology, Coney Island Hospital; and is a Professor in the Departments of Obstetrics and Gynecology and of Bioethics at Stony Brook University in Stony Brook, New York.

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is a long-standing phenomenon. Among the reasons for conscientious vaccine refusal¹ are (1) religious objections, (2) other philosophical objections such as a desire to live a natural life,² and (3) exaggerated concerns regarding vaccine safety.³ Many of the latter are based on discredited work linking vaccination with autism.⁴ Other parents may appreciate that vaccines are quite safe, but would protect their children from the minor risks of vaccines by relying on other children’s vaccination to prevent their own children from contracting the diseases in question.⁵ The degree of vaccine refusal varies. Some parents refuse all vaccines for their children. Others are willing to permit their children to receive certain vaccinations but not others, or accept vaccines on a delayed schedule.⁶

In the U.S., principled objections often receive legal exemption. All but three states⁷ allow religious exemptions to laws requiring vaccination for attending school or group childcare;⁸ 18 of these states⁹ also permit exemptions for personal or philosophical beliefs.¹⁰ The spectrum of religious, personal, and philosophical objections covered and the rigor with which these are investigated varies.¹¹

Public health vaccination strategy can reasonably differ by disease on the basis of disease severity and communicability. For example, 47 U.S. states mandate hepatitis B immunization for admission to school, day care, or both. In contrast, only 19 states have any requirement for hepatitis A vaccination.¹² Only measles-mumps-rubella and polio vaccination are required in all 50 states.¹³ Vaccination may be recommended, compulsory, or mandatory for school attendance.¹⁴ European nations rely more heavily on recommendations to obtain vaccination compliance

than do U.S. states.¹⁵ Because of the recent increase in the incidence of vaccine-preventable disease, some European nations have moved toward a more prescriptive approach. France recently increased the number of required vaccinations for school attendance in its mandatory vaccination policy. Italy also recently adopted a mandatory vaccination policy, but without provision for conscientious objection such as those found in most states in the U.S.¹⁶ The likelihood of school age children acquiring a disease may favor a program of mandating vaccination for school attendance. Similarly, there is less urgency to vaccinate children against a disease that generally is confined to adults.

Determining that a certain strategy is conducive to health does not necessarily imply that governmental power should enforce that strategy. Health must be balanced against other goods. For example, parents expose their children to the risks of full contact sports because they believe that these provide social and character benefits that counterbalance their health risks.¹⁷ The risks of injury from football are probably greater than the risks of grave consequences from varicella, but football is often encouraged (even though safer means of exercise and competition are available), while vaccination against varicella is mandatory. Thus, both parents and state agencies such as schools and public health departments balance health benefits against other factors. Parents and agencies may disagree regarding the appropriate decision. When such disagreement occurs, the balance between parents' prerogative to raise their children according to their values and the state's obligation to protect minors must take into account factors other than health and safety.

In this article, we first will discuss the science of vaccination, then the ethical issues as elucidated by previous work. We then will propose a rubric for analyzing situations in which parents and authorities differ regarding the need for vaccination. We will explain how this rubric provides a tool to accomplish this in a way that complements or improves on previous approaches.

Risks and Benefits of Vaccination

The factual bases for vaccine refusal have largely been scientifically refuted. There is no scientific support for the notion that vaccines overwhelm the infant immune system.¹⁸ Most additives in vaccines are safe in the absence of anaphylaxis to a component ingredient.¹⁹ No reputable study has suggested a link between autism and any vaccine.²⁰

Severe vaccine complications are unusual, but can occur. A 1994 report from the Institute of Med-

icine's Vaccine Safety Committee acknowledged several such complications.²¹ These included Guillain-Barré syndrome with diphtheria/tetanus (DT/Td/T)²² and oral polio vaccines,²³ brachial neuritis with DT/Td/T,²⁴ thrombocytopenia with measles-mumps-rubella (MMR),²⁵ a risk of polio in the patient or a contact from the oral polio vaccine,²⁶ a risk of death from vaccine-strain viral measles infection, and anaphylaxis to components of almost any vaccine. An updated report in 2011²⁷ also recognized a likely relationship between disseminated infection with the live virus varicella vaccine.²⁸ Rotavirus vaccine may be associated with intussusception.²⁹ The combined diphtheria-tetanus-acellular pertussis-inactivated polio-haemophilus B (DTaP-IPV-Hib) vaccine has some association with febrile seizures.³⁰ In the rare case that a vaccine causes a serious adverse effect, U.S. patients are potentially eligible for compensation through the National Vaccine Injury Compensation Program. This program, funded by the U.S. Health Resources and Services Administration, ensures that liability concerns are separated from both the vaccine manufacturer and healthcare provider and thus removes a potential barrier to maintaining high rates of vaccination.³¹

However, the risks associated with *not* vaccinating far exceed those of vaccination. Unvaccinated children are more likely than their vaccinated peers to contract vaccine-preventable diseases. For example, a retrospective cohort study between the years 1985 to 1992 reported that school-aged unvaccinated children were 35 times more likely to contract measles than those who were vaccinated.³² This study reported a higher relative risk among younger children, with those aged five to nine having a risk of measles 170 times that of their vaccinated classmates. The study also predicted that in communities with higher numbers of unvaccinated children, the incidence of measles will rise even in vaccinated children. In Colorado, children not vaccinated due to a personal belief exemption were 5.9 times more likely to acquire pertussis than their vaccinated peers. This relative risk increases to 10.6 if all nonvaccinators are included—not just those with a known personal belief exemption. In Michigan, geographic clusters with a high number of non-medical vaccination exemption are three times more likely to experience pertussis during an outbreak.³³

The protective effects of vaccinations apply to an entire community due to herd immunity or, in the absence of this, relative herd protection.³⁴ Without herd immunity a population may harbor a pathogenic organism indefinitely; but with herd immu-

nity, an outbreak, although possible, will be self-limiting. The percentage of immunized individuals required to attain herd immunity depends on the ease with which the disease is transmitted. A highly infectious disease for which a single infected person is expected to spread the disease to 15 people requires a higher proportion of the community to be vaccinated than does a less infectious disease for which an infected person can be expected to spread the disease to only two or three people.³⁵ Measles is highly contagious, probably requiring a vaccination rate of greater than 95 percent to attain herd immunity; the corresponding rate for diphtheria is estimated to be 79 percent to 84 percent.³⁶ This is at the low end of coverage for serious communicable diseases of childhood. Herd immunity also is affected by the efficacy of the vaccine. This ranges from 99 percent seroconversion for the measles vaccination³⁷ to much lower rates for the influenza vaccine.³⁸ Absence of sufficient herd protection can produce dramatic outbreaks, like the outbreak in California of 113 cases in early 2015.³⁹ Those at risk include children too young to be vaccinated,⁴⁰ those who cannot be vaccinated for medical reasons,⁴¹ and those who do not derive immunity from the vaccine.⁴²

Vaccine refusal puts people who do not vaccinate at higher risk of complications if they contract a vaccine-preventable disease. The herd protection effect increases the expected age at which an unvaccinated person is likely to encounter an infectious agent and contract a disease. Some diseases for which vaccination is required have more severe consequences in adults. For example, in the prevaccination era, the average age of a patient with measles was just under five years old. However, a model suggests that if vaccination coverage was 20 percent below the threshold for herd immunity, the average age of a case of measles would be 19.1 years. This increases the risk of serious complications by a factor of 4.5. Severe outcomes would also be expected to increase in cases of varicella (by a factor of 2.2) and rubella (by a factor of 5.8).⁴³

Inconsistency of Vaccination Regulation

When a parent refuses to vaccinate a child, both the child (the “index child”) and the surrounding community are endangered by this decision. Because of the risks to the index child, communicability is not the exclusive determinant of vaccine policy. For instance, vaccination against tetanus, a noncommunicable infectious disease⁴⁴ that can be prevented by other measures following possible exposure, is mandatory for school attendance in most U.S. jurisdictions.

Beyond this, U.S. vaccination policy among the states is hard to rationalize. Maps that list requirements for different vaccines show poor overlap in vaccination requirements for different diseases, although some patterns exist. More states require vaccination for more-severe pathogens. Also, states are more likely to require vaccination against pathogens for which vaccines have long been available (for example, tetanus/diphtheria/pertussis and pneumococcus).⁴⁵ While individual state rules reflect local state policy processes, there is little uniformity in statutes for newer vaccines (for example, human papilloma virus and influenza), age of population required to be vaccinated (schools, day care centers, colleges, *et cetera*), breadth of exemptions permitted, or degree of scrutiny that different states apply to requests for exemptions.⁴⁶

Vaccine policy in the U.S. is inconsistent with governmental approaches to other medical interventions and to nonmedical practices. Even when early intervention programs for major psychomotor problems or visual impairment are available gratis or at low cost to preschool and school age children, parents are not required to take advantage of these programs. These optional, non-invasive interventions are much more likely to benefit a child’s health than immunization against tetanus or varicella.

Social acceptability may influence the tolerance of societal harms. For example, a nine-year-old child can play full contact hockey but cannot come to school if not immunized against tetanus. Perhaps this is because religious beliefs leading to vaccination refusal are less respected by the general population than the social prestige that most in the U.S. associate with contact sports.⁴⁷ Clearly, governmental requirements in the U.S. that are designed to protect children’s health and safety have no consistent grounding in a balance of harm and benefit, let alone a comprehensive vision.

The Ethics of Vaccination Requirements

The question, then, is whether bioethical analysis can rationalize this area of concern. In a strictly majoritarian democratic society, the discussion would end there; *vox populi vox dei*,⁴⁸ as it were. However, society looks to other germane ideals. These, however, may conflict with each other in their application, as well as with democratic processes. First, society, often through government, has a *prima facie* obligation to protect the vulnerable. When the state does this, it is called “police power” in U.S. law.⁴⁹ Second, liberal ideals demand that people be allowed to pursue their own vision and act upon their own beliefs whenever possible. A third, con-

troversial, ideal is multiculturalism. This ascribes to individuals the prerogative of associating together in communities within a sovereign state in which they can realize their values and practice their customs.⁵⁰ Irrespective of any of these other values, the integrity of the family and the default power of parents to make decisions has been acknowledged legally⁵¹ and ethically.⁵² This includes rearing children in accordance with group beliefs and values. These five conflicting principles—majoritarianism, protection of the vulnerable, liberalism, multiculturalism, and respect for the value of the family—have been reconciled inconsistently. As Levin and colleagues noted, a regime of inconsistency in balancing minority values against considerations related to the health and safety of children is likely to discriminate against the marginal and the unpopular.⁵³

Approaches Based on Medical Ethics

Proposed bases for resolution of conflicts over healthcare decisions regarding individual children fall into several categories. These include child autonomy, best interests, the harm principle, family-oriented views, and micro-economic analysis.⁵⁴ The best interests standard has been applied to childhood vaccination by Chervenak⁵⁵ and by Dawson.⁵⁶ Both authors prefer persuasion, but are willing to invoke governmental power to compel vaccination for serious illnesses. But the best interest standard tends to focus primarily on physical or health-related interests, and does not generally account for the psychological, familial, religious, or cultural interests of a child that may play a part in vaccine refusal.⁵⁷ Furthermore, issues of probability, proximity, and severity are difficultly to reconcile. That is, it is not immediately clear whether it is in the best interest of a child to undergo the risk of one painful injection and a potentially mild injection-site reaction, versus the small probability of contracting hepatitis A. Thus, under the best interest standard, a surrogate decision maker must determine the highest net benefit among the available options, assigning different weights to interests the patient has in each option and discounting or subtracting inherent risks or costs.⁵⁸

Douglas Diekema prefers to use an approach based on John Stuart Mill's harm standard as the touchstone for intervention in the case of vaccination, as Diekema argues it is more reasonable and more precise than the best interests standard.⁵⁹ He further qualifies the nature of the harm that he would accept as a trigger for U.S. states to override parents, restricting it, for example, to situations in which the threat of harm is serious and urgent, rather than

public health considerations more broadly. Applying this standard to vaccinations, Diekema finds state intervention warranted only in unusual circumstances. Others, such as Jessica Flanigan⁶⁰ and Roland Pierek,⁶¹ have used the harm principle to justify a more vigorous approach to required vaccinations. However, the harm standard can be indeterminate in practice; Giles Birchley documented that two judges in the same jurisdiction used the harm principle in virtually identical child custody cases to reach opposite conclusion.⁶² Lainie Friedman Ross's restrained parental autonomy standard has the advantage of including all familial interests in the calculus, but does not solve the problems of weighing probability, proximity, and severity consistently and uniformly. Indeed, it is impossible to eliminate these problems as long as different decision makers with different values are adjudicating these conflicts.

Approaches Based on Public Health Ethics

Widespread compliance with vaccination mandates is required to prevent communicable diseases that give risk to outbreaks and epidemics. Therefore, the ethical analysis of this phenomenon also belongs to public health ethics with its communitarian focus, rather than solely to traditional medical ethics with its focus on the individual.

It is hardly questioned that governments may act to "protect the lives, health . . . comfort and general welfare of the people," termed "police power" in U.S. law.⁶³ Governments have asserted this power for at least 4,500 years.⁶⁴ The United Kingdom's Nuffield Council on Bioethics outlines an "intervention ladder" to rank the different ways that governments can impact individuals' choice.⁶⁵ Although the Nuffield Council outlines eight specific options, the ladder "rungs" can largely be collapsed into four areas—education, organization, incentivization, and compulsion. A state that wanted to increase childhood rates of vaccination could mount public service campaigns (education). It could operate a medical care system that ensured that children were seen by a physician regularly (organization). It could pay parents to vaccinate their children or direct physicians to vaccinate all children unless a parent raised specific objections (incentivization). Or, it could require that children receive the vaccination as a condition for school attendance (compulsion). Public health ethics asks when governmental intervention is appropriate to effect policies that are themselves, other things being equal, desirable.

Marcel Verweij has stated that the two most plausible "ethical allies" of public health are "the harm

principle and the consequentialist perspective.”⁶⁶ Jessica Flanigan relies on the harm principle to assert that policies requiring vaccination are appropriate provided that (1) the illness is contagious, (2) those who are exposed to the risks of transmission are not liable, (3) vaccination is necessary and effective at limiting contagious transmission, and (4) vaccination does not violate rights of self-defense (that is, that recipients do not have medical conditions that make vaccination dangerous to them).⁶⁷

Flanigan relies on an analogy between refusing vaccination and the celebratory firing of a gun into the air, seeing both actions as subjecting unknown individuals to the risk of harm. But one is an act of commission and the other an act of omission, and it is unclear ethically whether these ought to be regarded as equivalent.⁶⁸ Furthermore, this analogy does not address the likelihood of the harm. An analogy to a legal act that causes trivial but finite harm, such as driving with small amounts of blood alcohol, would also be apt, but would point to the opposite conclusion.

We now turn to Verweij’s second “ally,” consequentialism. This perspective is applied in a way that conceives of benefits to a community or a society as a whole as being greater than the sum of individual benefits.⁶⁹ Public health ethicists tend to emphasize the collective rather than the individual. Reducing a health risk is characterized as a *public good*, which Richard Arneson defines as follows: “[A] good is public according to the degree to which it exhibits three features: (1) a unit of the good consumed by one person leaves none the less available for others (jointness), (2) if anyone is consuming the good it is unfeasible to prevent anybody else from consuming the good (nonexcludability), and (3) all members of the group must consume the same quantity of it.”⁷⁰

Angus Dawson adds an additional element to the definition, that the public good “cannot be created by any individual alone: it takes collective efforts.”⁷¹ He also omits the third of Arneson’s requirements. This is appropriate, at least in a public health context, because exposure to disease will vary from person to person. Thus, for example, a program to test lead levels in children will benefit those exposed to lead-based paint from old houses more than other children who live in new housing with lead-free paint. The children more likely to be exposed would “consume” more health improvement than those less likely to be exposed.

Since herd immunity confers protection from communicable diseases on immunized and unimmunized people alike, it is said to be a public good,

as well as a private good for the vaccinated individuals.⁷² However, categorizing herd immunity as a public good does not demonstrate either that individuals are obliged to take the steps necessary to achieve it or that the government should pursue that good. An even stronger argument is that the existence of a public good does not *per se* justify the state’s use of any of the four tools at its disposal to bring that good about. At least eight hurdles remain before the state may use a given measure to try to procure the good.

First, the putative public good may not be, in fact, a good. This hurdle is easily cleared by vaccination programs. A second possible problem is that the good may not be important enough—absolutely or relatively—to warrant state action. Governments have finite resources. A program to landscape municipal thoroughfares would constitute a public good, but might best be shelved due to competition for resources by more urgent needs. A third and related hurdle is that a program may be sufficiently controversial that disruption caused by the program exceeds its value. In the case of vaccination, the disease in question must have sufficiently grave consequences to merit that vaccination be required.⁷³

Fourth, no good is exclusively a public good, as governmental programs create direct private goods for those who create and sustain them. This can lead to influence by such individuals to maintain or expand their programs even when the value of these programs diminishes. Fifth, the creation of a public good may cause so much harm to a minority that it seems grossly unfair to institute the program. A fictional example found in two widely read U.S. works is a lottery to kill a few people for the entertainment of a large population, which is presumed to be a public good.⁷⁴ Sixth, even if a measure is generally acceptable in theory, the burden of a government campaign that is strict enough to bring about the public good in question can cause unreasonable harm.⁷⁵ This is not the same as the previous hurdle; here it is enforcement, rather than the measure itself, that creates the harm. In New York City, fines are unable to control extensive, traffic-clogging double parking. The city tolerates this practice rather than escalating to towing, license suspension, or imprisonment, all of which would be considered disproportionate to the offense. Seventh, a measure that is good in isolation may not be as good when many similar measures are aggregated. Childhood immunization recommendations in various European nations include vaccines against 17 diseases.⁷⁶ Other diseases such as typhoid and yellow fever can be prevented using vaccines, but these are not given in

nations that have temperate climates and good sanitation. Further progress may yield vaccines against other flavivirus diseases such as dengue and Zika, human immunodeficiency virus, malaria, and other epidemic diseases. It may be tempting, especially in tropical nations in which many of these diseases are epidemic, to add some of these to childhood immunization protocols. It may also be possible to prepare vaccines against a wide variety of mild respiratory pathogens. The proliferation of vaccines may result in pressure to give small children many injections at great cost and considerable discomfort. Thus, a public good that is *prima facie* desirable may pose a problem in a broader context.

Finally, the good may simply be inconsistent with the values of society. Consider a hypothetical nation in which 80 percent of the inhabitants adhere to Christian Science beliefs and do not believe in vaccination. The government is likely to refuse to require vaccination, and may not even subsidize vaccination for those who want it for their child.

In summary, many vaccines are sufficiently effective to largely immunize individuals and to achieve herd immunity in comprehensively immunized populations. It is generally accepted that sovereign states have the power to restrict the freedom of their citizens to improve their health and safety, but that this power is not absolute. Most agree that parents are presumed to have at least default authority to make decisions on behalf of their child. We must balance the children's interest in health against their social, relational, and religious interests when deciding whether to override parental refusal of vaccination. Yet, there is no consistent approach to weighing this balance. At the same time, herd protection is a public interest, often expressed using the concept of public good. Here, too, the magnitude of the public good must be balanced against the considerations of individuals and families, as well as against competing public goods.

A Test to Provide a Template for Analyzing Vaccination Policy

In this section we will apply to vaccination policy a test for adjudicating among parental interests (including their religious and cultural beliefs and practices), child welfare, and societal needs. This test, which has been proposed before in a slightly different form,⁷⁷ balances individual liberty and respect for cultural difference against the protection of vulnerable children. In the context of U.S. constitutional law, it balances the right to free exercise of religion against the requirement that government not unduly favor religion. This test supplies a

balanced and transparent approach that respects all parties. We will not address the important question of whether religious views are privileged over other conscientious beliefs. The interested parties here include children whose parents refuse vaccination, children whose parents approve of vaccination but who are unable to benefit from it, society as a whole (which is interested in both freedom and in public safety), the parents themselves, and possible minority groups to which the parents belong.

A detailed justification and theoretical basis for this test has been presented elsewhere.⁷⁸ This test is presented in table 1.

The test balances societal values and imperatives against minority values and interests. While not explicit, the need to balance risks and benefits is implicit in all elements of the test. On the other hand, it is not simply a comparison of risks and benefits. First, it is explicit about which harms to children constitute unreasonable burdens, while burdens that society should be expected to tolerate are more open-ended. Second, the test's "comparability of effect" constraint uses society's overall risk tolerance as one benchmark for assessing risk to a particular child. Third, the "benefit/harm" constraint considers not only direct harms from an undesirable practice, but also possible harms from enforcement programs.

The test has similarities to Diekema's harm principle analysis, but there are differences as well.⁷⁹ Unlike Diekema's test, which was written as an ethical response to individual conflicts, this test was conceived to provide legal and ethical responses to public health questions confronting policy makers. There may be situations in which Diekema might allow exemptions but where this test's consideration of public health considerations, as reified in the "indirect effects" basis, would require vaccination. Furthermore, unlike Diekema, this test does not require imminent harm to overturn a parental decision. This test, then, is complementary to Diekema's approach. The test is pragmatic, with utilitarian elements. It contrasts with deontic approaches such as the best interests approach, as this test also allows consideration of the needs of other members of the family in determining whether state interference is warranted.⁸⁰ While transparent and balanced, the test is not absolutely determinative. Different societies have different views as to what is an unreasonable burden upon itself or its members, and what constitutes a substantial burden on a child. However, the "comparability of effect" prong prevents society from using public health measures as an excuse to disadvantage minorities.

While others have suggested that different diseases should be treated differently with respect to compulsory vaccination,⁸¹ we believe that this test provides a template that can be used to analyze which vaccinations should be required.

Application of the Test to Various Vaccinations

We first discuss the test with regards to vaccination in general and then as applied to vaccinations for several specific diseases. As noted above, there are various preventive options such as testing of sight, hearing, and cognitive function that enhance children's health and that are even less invasive than vaccination, but that are not required. Society is willing to grant exemptions for the harms and costs created by refusal of early intervention, which seems directly analogous to childhood vaccination. Therefore, a vaccination refusal that subjects children to the same or lower benefit/harm ratio as the risks of declining sensory testing or early cognitive intervention should be tolerated. This constraint is found in Prong 1, Basis 2, "Direct effects," of this test, that relies on Prong 2, Constraint 2, "Comparability of effect" and Prong 2, Constraint 3, "Benefit/harm" of this test. Although universal immunization against any communicable disease provides a public good, vaccination is offensive to many parents, for a majority of reasons. The common good is incorporated in Prong 1, Basis 1, "Indirect effects," of this test. The term reifies the benefits of universal immunization and the harms, or lack of benefits, of failure to immunize. The term provides a contrast to Prong

1, Basis 2, "Direct effects," which describes private goods or harms.

Refusal of early cognitive intervention produces not only costs to the child and family, but costs to society. These consist of diversion of resources to manage the disability. Therefore, Prong 2, Constraint 2, "Comparability of effect," as applied to both Prong 1, Basis 1, "Indirect effects," as well as Prong 1, Basis 2, "Direct effects," seems to mandate that what we tolerate for early cognitive intervention refusal (for example), we should tolerate for vaccination refusal. This could apply in one of two ways, either to justify both compulsory early cognitive intervention and vaccination mandates, or to require legal exemptions from both. Thus, at this point in the analysis, either or both should be required, but not one of these without the other.

However, there is another factor to consider. Vaccination, but not early cognitive intervention, prevents transmission of communicable disease. For this reason, Prong 2, Constraint 2, "Comparability of effect" does not rescue parent refusal of vaccination. Achieving herd protection is a major reason, under Prong 1, Basis 1, "Indirect effects" to require vaccination. Nothing comparable applies to early cognitive intervention, refusal of which does not make other children ill.

However, tetanus immunization is required in U.S. states, even though tetanus is not communicable. Its effect on infected children is devastating. It causes much prolonged suffering and frequent death. But it is rare in developed nations, with an

TABLE 1. A test for adjudicating among parental interests, child welfare, and societal needs

Limitation of parental power. A state may limit a decision or practice involving a child's health if any of the following two bases exist, but only if none of the constraints in the second prong apply:

Prong 1. Bases for limiting parental practices. Limitation is warranted if the decision or practice has sufficiently adverse effect outside the family or minority group such that it creates unreasonable burdens for either of the following two bases:

Basis 1. Indirect effects: Society as a whole, or members of society outside the family or minority group.

Basis 2. Direct effects: Children belonging to the family or minority group, by:

- a. Creating a substantial chance of death or of major disruption of a physiological function, or
- b. Creating other objectively severe harmful effects, such as malnutrition or major psychological morbidity.

Prong 2. Constraints on government action. Notwithstanding the bases in the first prong, a state should restrict parental action only if none of the following constraints apply:

Constraint 1. Likelihood of effect. The harm underlying the restriction must be:

- a. Actual, rather than hypothetical, and
- b. Likely, rather than unlikely or rare.

Constraint 2. Comparability of effect: The harm underlying the restriction must be of a magnitude greater than harms typically tolerated for mainstream practices comparable in both impact and type of practice.

Constraint 3. Benefit/harm: Benefits of the restriction to all parties concerned should foreseeably exceed overall harms.

incidence under one per one million.⁸² Tetanus is rare even in unvaccinated children.⁸³ The rarity of the disease invokes Prong 2, Constraint 1, “Likelihood of effect,” while the overall low burden on society does not preclude exemptions based on Prong 1, Basis 1, “Indirect effects.” Thus, conscientious exemptions for tetanus vaccination are reasonable. In practice, however, the tetanus vaccine is combined with those for diphtheria and pertussis. These two communicable diseases are serious and are common in unvaccinated populations, so they should require vaccination without nonmedical exemption. So for practical purposes, the issue is moot.

While a coryza vaccine does not currently exist, coryza is, in important respects, the opposite of tetanus. It is a highly communicable infection transmitted by aerosol. It will readily spread in crowded environments like schools. The effect on those who have coryza is a few days of discomfort and possibly absence from school or work.⁸⁴ Coryza transmission among children is likely, so that coryza (unlike tetanus) passes Prong 2, Constraint 1, “Likelihood of effect.” However, increasing the chances of one’s child catching cold does not subject the child to unreasonable risk under Prong 1, Basis 2, “Direct effects,” nor is coryza so serious, so that (if a vaccine were available) the cost to society of sporadic outbreaks would not be substantial enough to justify denying religious exemptions under Prong 1, Basis 1, “Indirect effects.” As with tetanus, but for a different reason, parents should not be compelled to vaccinate their children against coryza, if a vaccine were to become available.

Polio occupies a third category. It carries a high mortality, and has a high rate of serious, permanent neuromuscular complications, both immediate and delayed. It is readily communicable in children.⁸⁵ Factors that might lead to outbreaks, such as vaccination refusal, affect society and its members under Prong 1, Basis 1, “Indirect effects.” Children who would otherwise benefit from vaccination may get polio because some are too young to be vaccinated, some cannot be vaccinated for medical reasons, and some fail to acquire immunity through vaccination. Even religious communities are not totally insular, so children in relatively closed communities (such as private Christian Science schools) may infect children outside the community. Thus, vaccination refusal creates an unreasonable risk to children outside that community. So, both Prong 1, Basis 2, “Direct effects,” and Prong 1, Basis 1, “Indirect effects,” allow categorical vaccination requirements. Certainly, the disease is real and is not rare, absent vaccination, so Prong 2, Constraint 1, “Likelihood

of effect,” does not vitiate government action. The magnitude of the harm caused by failure to vaccinate is greater than the magnitude of the harm caused by any permissible practice in society, so Prong 2, Constraint 2, “Comparability of effect,” does not apply. The external costs incurred in enforcing compliance (education, punishment, *et cetera*) are unlikely to be worse than the effects of foregoing herd protection. Governments may, therefore, ethically require vaccination for polio over all nonmedical objections.

Similar analysis, which we will not conduct, is applicable to other vaccinations for childhood illnesses. It is important to note that the terms “rare” and “substantial” used in the test are purposely left as subjective and without absolute numerical qualifiers. In a democratic, liberal society as the U.S., society (through elected representatives and the judiciary) can and should set the threshold values for such determinations.

CONCLUSION

In our liberal society, the rights of parents to raise children as they see fit (often according to religious or deeply held personal beliefs) may conflict with the duty of the government and society to protect the welfare of children. In the U.S., these conflicts have not been settled in a manner that is uniform, logical, nor consistent. The proposed test, as discussed above, offers a concrete and formal manner to evaluate such conflicts. It does not force a government or society to intervene—only states when it *may* do so or when it *may not*. Thus, for some vaccinations, based on the individual medical characteristics of the disease and the risks of being unvaccinated, the test would suggest that religious and conscientious exemptions are ethical. However, for vaccinations protecting against other diseases that are more severe or easily transmitted, the test would suggest that the government may impose such laws that prevent such conscientious objection. As medical data accumulates surrounding the relative benefits and risks of both vaccination and nonvaccination for given diseases, the discussion and application of the test may change. Currently, the test would suggest that for many infectious diseases, state laws that ban nonmedical exemptions are ethical and liberally permissible.

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NOTES

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Nursing Ethics Huddles to Decrease Moral Distress among Nurses in the Intensive Care Unit

Marianne C. Chiafery, Patrick Hopkins, Sally A. Norton, and Margie Hodges Shaw

ABSTRACT

Background

Moral distress (MD) is an emotional and psychological response to morally challenging dilemmas. Moral distress is experienced frequently by nurses in the intensive care unit (ICU) and can result in emotional anguish, work dissatisfaction, poor patient outcomes, and high levels of nurse turnover. Opportunities to discuss ethically challenging situations may lessen MD and its associated sequelae.

Marianne C. Chiafery, DNP, MS Clinical Bioethics, PNP-C, is an Assistant Professor of Clinical Nursing at University of Rochester School of Nursing; and is an Assistant Professor of Medical Humanities and Bioethics at the University of Rochester School of Medicine in Rochester, New York. *Marianne_Chiafery@urmc.rochester.edu*

Patrick Hopkins, DNP, NNP, RN, is an Assistant Professor of Clinical Nursing at the University of Rochester School of Nursing. *Patrick_Hopkins@urmc.rochester.edu*

Sally A. Norton, PhD, RN, is an Associate Professor of Nursing at the University of Rochester School of Nursing. *Sally.Norton@urmc.rochester.edu*

Margie Hodges Shaw, JD, PhD, is an Assistant Professor at the University of Rochester School of Medicine and Dentistry. *Margie_Shaw@urmc.rochester.edu*

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Objective

The purpose of this project was to develop, implement, and evaluate the impact of nursing ethics huddles on participants' MD, clinical ethics knowledge, work satisfaction, and patient care among ICU nurses.

Sample and Setting

The sample, 32 nurses from three ICU settings in an 800-bed tertiary academic medical center, participated in six nursing ethics huddles over a two-month period.

Methods

Alvita K. Nathaniel's Theory of Moral Reckoning guided development of the nursing ethics huddle process.¹ The Moral Distress Thermometer was administered at three data points: baseline level of MD, and pre- and post-huddle to determine changes in the subjects' level of MD.² Focused content analysis was used to analyze qualitative responses from questionnaires about the subjects' perception of the effect of the huddles on work satisfaction and patient care. Knowledge attainment was evaluated via open-ended short-answer questions.

Results

Overall, use of nurse-ethicist-led nursing ethics huddles was associated with improved quality of work life, patient care, and clinical ethics knowledge. The change in pre- and post-nursing ethics huddles MD scores was statistically significant ($p < 0.0001$).

The nature of nursing requires that ethical decisions are made and enacted daily. Nurses are members of a healthcare team, and individual team members may have differing values, beliefs, and obligations in a situation. Moreover, the values and beliefs of the patient and his or her family are paramount and contribute to decision making. With so many stakeholders, conflict about what is the right course of action is not uncommon. Ultimately, the nurse may not agree with the final decision, yet must enact the decision, creating a personal ethical dilemma.³ Nurses may witness actions they believe violate ethical standards of care and behavior, and may feel conflicted as to how to proceed. This conflict was first described by Andrew Jameton as “moral distress” (MD), which he defined as the emotions that a nurse feels when the nurse believes that she or he knows the right action to take, but is constrained from taking that action due to perceived institutional obstacles.⁴ The definition has evolved to the recent one by Carina Fourie as the “psychological response to morally challenging situations such as those of moral constraint, moral conflict, or both.”⁵

The impact of MD on the nurse can be significant and includes physical and emotional responses such as anger, sleeplessness, and guilt.⁶ Nurses report a direct relationship between MD and patient care and outcomes.⁷ Elizabeth Gingell Epstein and Ann Baile Hamric note that unresolved MD may result in moral residue, defined as an accumulation of MD that continues to build, or “crescendo” to high levels.⁸ Unmitigated or unresolved MD may result in nurses leaving the environment and, ultimately, the profession.⁹ Causes of MD include:

1. Poor interprofessional communication,¹⁰
2. Actions that prolong the patient’s death,¹¹
3. Actions that violate patients’ autonomy,¹² and
4. Medical interventions that are viewed as futile or nonbeneficial.¹³

Courtenay R. Bruce, Susan M. Miller, and Janice L. Zimmerman noted that intra-team disagreements create MD and are often the result of poor communication about patients’ prognosis and provision of nonbeneficial treatment.¹⁴

Nurses use multiple means to attempt to ease MD, including conscientious objection,¹⁵ informal discussion with peers, education, and formal ethics debriefings.¹⁶ There are few reports in the literature of evaluation of the effectiveness of interventions to decrease MD. Most reports focus on case studies and anecdotal reports. Efforts are being made to address this gap in knowledge. A small pilot study by Rose

Allen and Eve Butler indicated that formal ethics education may decrease MD and intent to leave among ICU nurses.¹⁷ Lucia D. Wocial and colleagues found that MD among staff decreased with the implementation of unit ethics rounds.¹⁸ These studies are helpful to suggest effective ways to decrease MD, and more work is necessary. Thus, evaluation of an intervention intended to diminish MD was identified as an area that needs more study and quantitative analysis. The purpose of this article is to describe the implementation and evaluation of nursing ethics huddles as an intervention to decrease MD.

INTERVENTION

Nursing ethics huddles (NEH) are confidential, unit-based small group meetings for nurses to discuss ethically troubling cases. Nathaniel’s theory of moral reckoning (TMR)¹⁹ and Rosamond Rhodes and David Alfandre’s model for clinical ethics consultation²⁰ informed development of the NEH.

Nathaniel’s TMR recognizes the complex nature of MD and provides a framework to describe the process a nurse undergoes when faced with an ethical dilemma.²¹ (Refer to figure 1 for a schematic diagram of TMR.)

To develop the theory, Nathaniel undertook qualitative analysis of interviews with nurses who recalled important ethically distressing cases from their professional lives. The theory describes the process a nurse undergoes as attempts are made to grapple with an ethically loaded situation. When faced with an ethical dilemma, a nurse weighs multiple factors to make a decision as to how to proceed.²² After the chosen option has been enacted and outcomes realized, the nurse reflects upon the case in order to come to terms with the consequences. This is a process of “reckoning.”²³ The work of “reckoning” is an individual and personal process of making sense of a morally troubling situation, and coming to terms with the consequences of one’s own actions. Unresolved feelings of inadequacy or of having perpetuated a wrong may result in persistent MD.²⁴

In TMR, an assumption is made that an ethical dilemma has more than one correct solution, thus the nurse experiences uncertainty as to how to proceed and is placed in a “situational bind.”²⁵ Theoretical concepts of TMR include those of ease, situational bind, resolution, and reflection. *Ease* is defined as a state of comfort and freedom from worry about ethical concerns.²⁶ When in a state of ease, the nurse’s core personal and professional beliefs

are aligned with daily work life, and there is a feeling of congruency and integrity. However, an ethical dilemma arises, which Nathaniel terms a *situational bind* that jars the nurse from a state of ease.²⁷ This bind causes the nurse to question personal and professional identity, role expectations and integrity, and can engender feelings of self-doubt, tension, and anxiety. To relieve moral tension, the nurse explores options and considers new concepts to address the situational bind.²⁸ Exploration propels the nurse to a stage of *resolution*, in an attempt to “make things right and resolve tension.”²⁹ The nurse evaluates multiple factors in the situation, and makes a decision to “take a stand” or “give up.”³⁰ This is a complex decision, and the outcome has important implications for the future in terms of feeling good about the self, or carrying chronic feelings of regret. *Reflection* is a critical stage of the TMR. Careful post-situational analysis of the events and behaviors and reflection on the chosen plan of action by the nurse occur. Such feelings, especially ones of regret, may “last a lifetime.”³¹

Importantly, the actions of “remembering, telling the story, examining conflicts, and living with the consequences” fall under the realm of reflection.³² Nathaniel notes that a nurse is more likely to tell the story in an environment of sympathetic caring. Telling the story helps the nurse make sense of the experience and fosters personal growth due to self-discovery, understanding other perspectives, and evaluation of conflicts. Positive outcomes include the attainment of wisdom and knowledge and

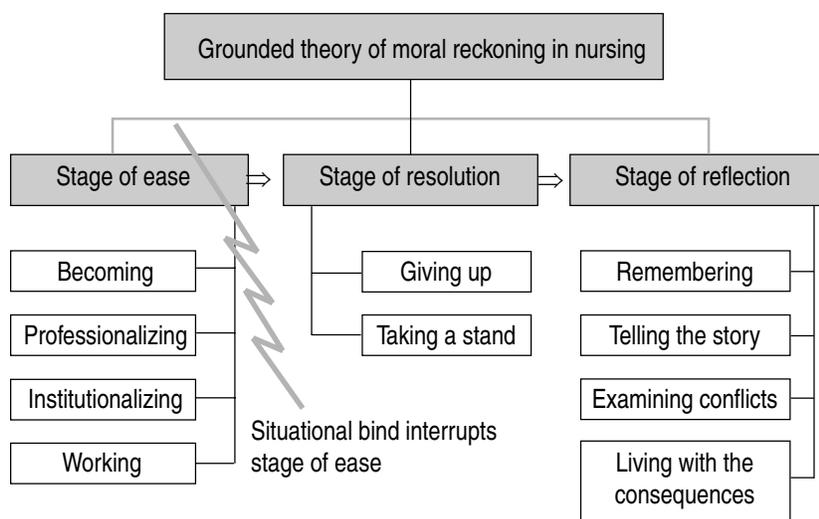
relief of emotional or psychological pain. As personal and professional conflicts are explored, the nurse may reconsider self-image, set limits for future cases of a similar nature, and evolve professional practice to reconcile with the new perception of self.³³ As a result of her work, Nathaniel recommends utilizing structured discussions with nurses about ethical dilemmas as a practice intervention.³⁴

APPLICATION OF NATHANIEL’S THEORY TO PROPOSED PROJECT

Nathaniel’s theory and descriptions of the experiences of nurses facing ethical dilemmas informed the development of, and provided the framework for, the proposed project. The project involved the creation of a structured intervention—nursing ethics huddles (NEH)—to address nurses’ MD. The NEH is a unit-based tailored intervention that uses active cases identified by the nurses as causing MD for discussion, including analysis of conflicting values and beliefs, application of ethical principles, and brainstorming positive ways to address the perceived problem. The NEH is a route, or method, for nurses to actively explore and attempt to work through a troubling ethical situation. The timing of the intervention is important, and designed to coincide with Nathaniel’s stage of resolution,³⁵ the desire to act upon an ethically distressing situation. As Nathaniel notes, nurses may choose to “take a stand,” yet some of the actions that nurses use when taking a stand may be in violation of professional practice,

such as enacting a slow code. (A slow code is the purposeful act of responding to a patient in cardiac arrest without the usual timeliness and rapidity because of the nurse’s personal belief that providing cardiopulmonary resuscitation to this patient is wrong, and the patient should be allowed to die peacefully.) Other ways to take a stand include conscientious objection or outright refusal to implement a physician’s order.³⁶ A goal of the NEH process is to assist nurses to find ways to take a stand that do not violate professional practice standards or that come at great cost to the nurse or the institution. Nathaniel notes that taking a stand and giving up, the two possible pathways in the resolution stage, can occur within the same situation.³⁷ She notes that nurses may

FIGURE 1. Nathaniel’s Theory of Moral Reckoning in Nursing



Reprinted with permission. A. Nathaniel, “Theory of Moral Reckoning,” in *Middle Range Theory for Nursing*, ed. M. Smith and P. Liehr (New York, N.Y.: Springer, 2008), 282.

initially give up if the struggle to make things right is fraught with personal danger (loss of job, the anger of a team member or members), but then may come back to tackle the problem when better prepared.³⁸ Thus, a goal of the NEH is to help nurses who may have given up to find new or alternative ways to address the ethical problem in a way that is professional and positive. During the NEH process, the participants openly discuss the underlying values, beliefs, and ethical principles that are in conflict, with the goals of clarifying misunderstandings and hearing other points of view. When relevant, the facilitator also shares information about other factors that contribute to ethical decision making, such as laws, pivotal historic court cases, and exemplar ethical cases. This educational content about clinical ethics and the law is an important component of the NEH.

The NEH also provides nurses the opportunity to navigate Nathaniel's third stage, reflection, when nurses remember vividly the emotions and circumstances surrounding the ethical problem and tell and retell the story as they try to come to terms with, and work through, the unresolved ethical problem that lingers in their mind.³⁹ Nurses often share their stories of remembering and living with the consequences of their actions, even as the situation continues to unravel, so it may be helpful for nurses to have the opportunity via NEHs to remember, tell the story, and examine conflicts while the case is still active. These opportunities are included in the NEH process in the hope that nurses may find ways to improve the situation, rather than give up. Thus, NEH is an intervention developed to help nurses take a positive stand during an active and unresolved case. The ability to achieve this may result in fewer and less negative outcomes of living with the (bad) consequences of an ethically troubling situation, thus decreasing moral residue over the longer term. As noted earlier, the literature on TMR suggests that facilitated discussion, reflection, and shared group knowledge of a current or recent ethically charged case may empower the nurse to initiate a positive and helpful response to address a perceived ethical problem instead of simply giving up. The act of giving up, or not addressing the problem, may result in a nurse harboring feelings of regret for not taking purposive action, and a sense of hypocrisy for not being true to personal and/or professional values.⁴⁰ The goals of the unit-based NEH were to decrease moral residue or lingering doubts about self and professional role for the participants, increase feelings of empowerment, and boost positive feelings about the work environment.

Rhodes and Alfandre's Model for Clinical Consultation provided structure for the NEH. Key steps of the model are:

1. Collect all relevant data,
2. Identify ethical principles,
3. Discuss conflicts and information gaps,
4. Determine the ethical question,
5. Decide which principle has priority,
6. Ascertain if more information is needed,
7. Evaluate the decision or outcome, and
8. Determine next steps to address the concerns.⁴¹

Each NEH starts with the nurses selecting the case and presenting history and key points. A nurse-ethicist facilitates group discussion that includes reflection, clarification of values of all stakeholders, ethical principles in tension, identification of conflicts, and pertinent educational points such as medical information, law, policy, and historical case precedents. The NEH concludes with identification of "next steps" and development of a plan of action to address the concerns in a constructive and professional way.

METHOD

Study Question

What effects do NEH have on nurses' experience of moral distress, clinical ethics knowledge, work satisfaction, and patient care in three adult critical care units in a university-affiliated medical center in upstate New York?

Purpose

The purpose was to evaluate a nurse-led unit-based approach to alleviate moral distress and increase ethics knowledge and work satisfaction among critical care nurses.

Approvals

The project was assigned exempt status by the institution's Research Subjects Review Board. The hospital's chief nursing officer and key nursing leaders approved and supported the project.

Setting and Population

Hospital nursing administrators in an 800-bed university-affiliated tertiary care medical center in upstate New York were aware that ICU nurses were experiencing difficult ethical situations frequently, and sought a means to address the problem. Three units volunteered to participate and were included in the initial NEH program: adult burn-trauma ICU (BTICU); adult mixed surgical ICU, which consists

of six ICU beds and eight progressive care beds (SICU); and adult medical ICU (MICU). Nurses who work in the selected settings were invited to participate. Participation was voluntary. The NEH was held during work hours, so the 32 nurses who agreed to participate were scheduled to work, or voluntarily participated during their time off, indicating co-operation and a readiness to engage in the NEH. Two nurses left before the NEH started, due to patient care needs. The demographic data of the sample was similar to the ICU hospital nurse employee population. (Refer to table 1 for demographic data.) Data included information about years worked, to examine relationships between MD/moral residue, and length of time practicing as an RN, and information about number of NEHs previously attended to assess if there might be a “dose effect,” that is: Does the number of exposures to huddles effect the level of MD?

Mixed Methods Study Design

The Moral Distress Thermometer, developed by Lucia D. Wocial and Michael Weaver,⁴² a visual analog scale that ranges from zero to 10 (with 10 indicating the highest level of MD) was used to obtain a

quantitative measure of MD at three points (refer to figure 2, project design overview). Nurses may present to the NEH with moral residue that might affect reported level of MD for the case at hand; therefore before the case was selected, the nurses reported how much MD they experience in general in their work setting (MD baseline). Participants completed a pretest/post-test to measure moral distress before (MD pre) and immediately after (MD post) the NEH. To determine changes in MD before and after the NEH, the difference between the pre-huddle MDT score (MDT pre) and post-NEH MDT score (MD post) was calculated. A negative number indicated a decrease in level of MD. A positive number indicated that the nurse felt increased level of MD after completion of the NEH. To examine relationships, paired *t*-tests were utilized.

Qualitative data were collected to ascertain the effect of the NEH on nurses’ experiences, perceived clinical ethics knowledge attainment, and sense of work satisfaction. Immediately after the NEH, nurses were asked to describe what they learned, what was surprising, and what still troubled them. One-week post-NEH, an email questionnaire was sent to all participants to elicit perceptions of the effect, if any, on work life satisfaction and patient care. Following the NEH, the facilitator interviewed the nurse managers to elicit perceptions about benefits, burdens, and challenges as a manager to facilitate attendance. Participants’ feedback and nurse managers’ responses were analyzed for content, the responses were coded, and the content themes analyzed using well-established content analytic techniques. (Refer to figure 2 for project timeline.)

RESULTS/ANALYSIS

Quantitative Results

The number of participants changed in different parts of the study because nurses attended the huddle during work time, and some arrived a few minutes late or were called away before the end of the huddle. Overall, 32 nurses participated in some capacity; 30 signed in for the post-huddle impact evaluation; 29 completed the demographic data entirely; 27 completed all of the data points and the other five completed portions of the data collection.

Of the 32 participants, 30 reported baseline MD scores that ranged from one to eight prior to initiation of the NEH case discussion. The MDT change range was -6 to +2.3; the mean was -1.4; the median was -2.0; the mode was -2.0; the standard deviation (SD) = 2.1. Of the 30 nurses who reported baseline MD scores, 68 percent (*n* = 19) reported a decrease

TABLE 1. Demographic characteristics of project sample (*n* = 29)

Characteristic	<i>n</i>	%
Degree		
Associate	3	10.4
Bachelor's	21	72.4
Master's	2	6.8
Missing	3	10.4
Employment status		
Full-time	25	86.2
Part-time	2	6.9
Missing	2	6.9
Area employed		
Medical ICU	12	41.4
Mixed surgical ICU	7	24.1
Burn-trauma ICU	10	34.5
Attended a NEH the previous month		
Yes	7	24.1
No	19	65.6
Missing	3	10.3
Number of NEH attended previously		
0	7	24.1
2 - 4	12	41.4
5 - 8	6	20.7
> 10	2	6.9
Missing	2	6.9

in MD scores after participation in a huddle; 18 percent reported increased MD scores ($n = 5$), and 14 percent were unchanged ($n = 4$). MDT scores are shown in table 2.

Correlations

There was a significant difference in the scores for MDT pre ($M = 5.13$, $SD = 1.93$) and MDT post ($M = 3.73$, $SD = 2.09$) conditions; $t(27) = 3.55$, $p < 0.001$. Cohen's $d = 0.7$, indicating a moderate effect.

There were no statistically significant associations between number of years worked as a nurse and perceived levels of baseline MD, number of huddles attended and baseline MD scores, and baseline level of MD and years worked in the current unit.

Qualitative results

The NEN were analyzed for general themes as well as participants' and nurse managers' process and content evaluation.

Nursing Ethics Huddles Themes

Major themes noted during the huddles were:

1. Ambiguity in a situation resulting in confusion about the right action to take,
2. Poor intra-team communication,
3. Nurses' perception of limitations on sphere of influence and ability to advocate for patients,
4. Lack of knowledge about ethics, and
5. Concerns about patients' autonomy.

Of the 30 participants, 24 responded to the question of what bothered nurses most as they left the NEH; 38 percent ($n = 9$) expressed concern of ambiguity surrounding the case, 25 percent noted communication concerns ($n = 6$) and 38 percent ($n = 9$) noted decisions not in their control. A summary of the issues, education topics, and ethics content for each NEH are summarized in table 3.

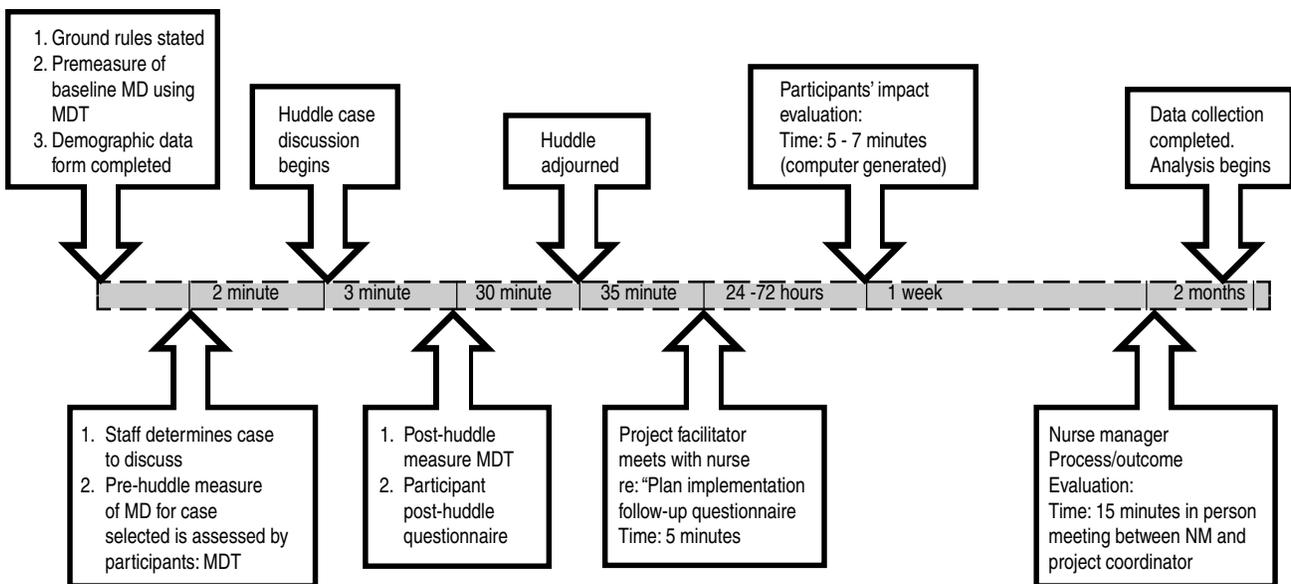
Participants' Email Survey Responses and Themes

The email survey response rate was 50 percent. All of the nurses indicated that they would attend a NEH again, and would recommend it to a peer. A majority of respondents expressed a sense of relief at discovering that others shared similar concerns and experienced MD. Some (40 percent) commented on the benefits of sharing emotions and feelings about ethically laden situations. Nurses noted that perspectives on a situation often changed as a result of the discussion ($n = 14$, 75 percent).

TABLE 2. Summary statistics for moral distress thermometer scores

Data collection point	<i>n</i>	Range	Mean	SD
Baseline score	27	1 - 8	4.1	1.9
MDT pre-score	29	1 - 9	5.1	1.9
MDT post-score	28	0 - 8.5	3.7	2.1
MDT change score	28	(-6) - 2.3	-1.4	2.1

FIGURE 2. Project design overview: ethics huddle process and evaluation



Nurses also commented on the knowledge they gained from the NEH about ethics and policy. Many noted that it was helpful to look at a case from different points of view and to gain ideas and knowledge that could be applied to future cases ($n = 10$, 63 percent).

One survey question sought to ascertain if the nurses felt that the NEH improved patient care. Of the 30 surveyed, 14 nurses responded to the question and half reported patient care was helped; half reported no help. None reported that patient care was worse. No participants reported that the NEH caused harm. A majority of nurses reported that the NEH helped them be better patient advocates, improved their ability to think through an ethical problem, and enabled staff to formulate effective plans of care, communicate more effectively, and use available resources more frequently.

There was an incidental finding from the project: some nurses reported higher levels of MD after the NEH ($n = 5$). Analysis of this group's responses indicated interesting findings and themes of high lev-

els of empathy and moral residue. The members of this group were at the far opposite ends of the spectrum in regards to time worked in nursing: four were senior expert nurses who had worked mostly in the ICU and one was a novice nurse who had been in practice for less than one year.

Empathy for Peers

One novice nurse stated, "I did not realize how hard this has been for my peers. It makes me feel badly." The literature identifies the progression of internal focus in a novice nurse to the development of a professional identity that includes a deeper awareness of the concerns of colleagues.⁴³ This comment indicates a progression along that development through a realization of a team ethos and the needs of team members, as well as others. Other nurses echoed this sentiment, but none quite so poignantly.

High Levels of Moral Residue

Responses from more experienced nurses indicated lingering distress about unresolved issues, es-

TABLE 3. Summary of NEH topics, ethical principles, and education content

Primary issues/concerns discussed	Ethical principles	Education
1 Withholding information from a patient	Truth-telling, veracity, and trust Paternalism	Research findings on patients' wishes re: disclosure Cultural considerations Ethically permissible reasons to withhold information
2 Patient denied liver transplant	Allocation of resources Justice Responsibility of recipient as steward of scarce resource	Transplant screening process Requirements of recipient Grieving process
3 MOLST form interpretation	Quality of life Autonomy Benefit versus burden Futility and nonbeneficial treatment	Proxy role and advance directives Futility and nonbeneficial treatment
4 Rescinding DNR order for OR procedure	Interprofessional communication Patient autonomy	Hospital policy re: temporary lifting of DNR status
5 Adult with developmental disability and disagreement with parents' decisions	Parental authority Standard of care Professional duty Beneficence Nonmaleficence	Capacity assessment Insights into parental actions Limits of parental authority
6 Patient seems to want to stop treatment, medical team planning surgery	Paternalism Autonomy Benefit versus burden Beneficence Nonmaleficence	Proxy role Goals of care Role of palliative surgery to provide symptom relief

pecially in interactions with other members of the healthcare team. Comments such as “Nothing ever changes” may indicate long-term unresolved ethical issues and a sign of moral residue. One nurse expressed frustration that suggestions to other team members were not taken seriously or were ignored. Another nurse reported that physicians respect contributions except when it is suggested that palliative care be involved in the care of critically ill patients.

The findings raises further questions: Is a group format not helpful for everyone? Does the NEH process need revision? Further study is needed. As a result of this new awareness, the NEH process expanded to include the facilitator asking if anyone feels worse at the conclusion of the NEH, and, if so, the participant is offered extra time to stay to talk individually with the facilitator.

Nurse Managers' Survey Results

The nurse managers (NM) focused on scheduling concerns and the impact of the NEH on staff, noting the importance of flexible scheduling. The NMs' comments were overwhelmingly positive, and all indicated that they would continue the NEH on their units. All noted that the NEH provided staff with the opportunity to think about ethical issues in a new way and to express concerns in a way that alleviates emotional stress, burnout, and compassion fatigue. One NM noted that the NEH helped staff distinguish an ethical issue that can be addressed by nursing action, from issues of policy or law. Additional benefits noted by the NMs were:

1. Provides support for staff,
2. Educational questions are answered,
3. Brings about a solution or plan for improvement,
4. NM learns of issues that may not have been disclosed otherwise,
5. Defuses tension, stress, compassion fatigue, and burnout.

DISCUSSION

Overall, the findings provide support that the NEH had positive effects: NEH lowered the levels of MD among most participants, participants noted knowledge acquisition that could be applied in the work environment, and improved patient care. The outcomes of this project are consistent with the literature on factors that trigger MD as evidenced by the themes of ambiguity about a situation, ineffective communication on matters that are important to nurses, and feelings of empathy for patients and peers that result in MD and moral agency. The indi-

cations from the subgroup of nurses who had higher MD scores after the NEH and evidence of moral residue are consistent with study findings by Cynda H. Rushton, Joyce Batchellor, Kaia Schroder, and Pamela Donohue, that suggest that nurses' level of MD increases with length of time worked.⁴⁴ The literature also indicates that nurses who have significant MD and moral residue must find ways to cope each work day, and may bury or ignore persistent MD, resulting in moral dulling. It is possible that the NEH broke down personal coping mechanisms and reopened old MD issues that remained unresolved. This is an area for further exploration.

Consistent with Nathaniel's model, NEH provide a forum for participants to reflect via remembering, telling the story, examining conflicts, exploring professional role, and forging a plan to take a stand or find ways to cope with problems that are not within their realm of influence.

The NEH also provided a mechanism for participants to develop important skills to address MD, evidenced by the unexpected finding that many reported learning better communication skills from the NEH. Terri Traudt, Joan Liaschenko, and Cynthia Peden-McAlpine explored the practices of nurses who do not display evidence of MD, to ascertain why they seem immune.⁴⁵ The authors found that nurses who are aware of their obligations as a moral agent, are able to take into consideration multiple perspectives and alternate views, explore possible alternative responses to a situation, and value good communication and relationships with key stakeholders are less likely to suffer from MD.⁴⁶

Recent literature suggests that MD can be viewed as an indication of moral integrity and moral strength, and so should not be viewed as necessarily bad. Edmund G. Howe noted, “we may want to strive, over time, to change our present professional-cultural view, from one that sees an expression of moral distress as a threat, to a professional-cultural view that welcomes these challenges.”⁴⁷ Providing nurses with a forum to voice concerns promotes professional integrity and a more transparent ethical culture. The work of Ann Baile Hamric and Elizabeth Gingell Epstein provides further evidence of the effectiveness of unit-based debriefings to elicit and address unit or system problems that contribute to MD.⁴⁸ The authors describe an MD consultation system that provides help on an as-requested basis. The structures of the meetings are similar to the format of this project: listen and clarify, discuss concerns and constraints, and develop a plan to move forward to address concerns. The authors found that nurses who participated in MD consulta-

tions described being more empowered, better able to engage on important issues, collaborate with other key stakeholders, and work to implement change.⁴⁹

This project provides evidence that nurse participation in a forum to discuss troubling ethical cases, such as the NEH, may lower aggregate and individual levels of MD. An intervention that can diminish the amount of moral residue that persists after each individual ethical dilemma may decrease the acceleration trajectory of moral distress. The end results of lower moral residue and improved work satisfaction may enable nurses to remain in the work environment longer and, ultimately, decrease staff turnover.

The study has some limitations. The sample size was small, potentially limiting replication. Nurses who attended the NEH were a self-selected group who may have a greater interest in ethics than their peers. The time frame for the huddles and evaluation was limited, and, since nurses were pulled away from patient care, their attention may have been only partially focused on the discussion, or they may have felt self-imposed pressure to return to their assigned patient. Thus their responses to the surveys may have been rushed, which may have resulted in less descriptive responses and some uncaptured data.

Some limitations must be considered in regards to the facilitator. The facilitator knew some participants from previous interactions, which may have affected some responses and resulted in participant bias, for example, participants who desired to help the facilitator have a successful project. Also, the facilitator has qualifications (graduate level education in clinical bioethics, clinical experience with the hospital ethics consultation team, and funding support from Nursing Practice) that may be challenging to replicate in other settings. Finally, interpretation of qualitative data is subject to personal bias by the facilitator.

CONCLUSION

The problem of MD is well described in the literature and continues to be a major topic of concern for the nursing profession; however, effective and proven interventions to ameliorate the problem are few. Outcomes from this intervention-based project indicate that the NEH diminished MD, increased ethics knowledge, and improved work satisfaction and patient care. The findings from this project indicate that other institutions may want to consider developing interventions that are similar to NEH, as a program to help nurses cope with ethical dilemmas in ICU settings.

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“I Would Do It All Over Again”: Cherishing Time and the Absence of Regret in Continuing a Pregnancy after a Life-Limiting Diagnosis

Charlotte Wool, Rana Limbo, and Erin M. Denney-Koelsch

ABSTRACT

Parents, after learning of a life-limiting fetal condition (LLFC), experience emotional distress and must consider options that impact the remainder of the pregnancy, their future lives, and family members. For those who continue, little is known about their long-term presence or absence of regret about their choice, the reasons for this feeling, or its impact on their life. The aim of this research was to examine the concept of *decision regret* in parents who opted to continue a pregnancy affected by an LLFC. The contextual factors, conditions, and consequences surrounding the presence or absence of regret were analyzed.

Data were retrieved from a cross-sectional study using the Quality of Perinatal Palliative Care and Parental Satisfaction Instrument. Participants were parents ($N = 405$) who experienced a life-limiting prenatal diagnosis and opted to continue their pregnancy. Secondary data analysis examined qualitative responses (121/402) to an item addressing regret. Dimensional analysis was

used to examine data, identifying context, conditions, and consequences associated with the presence or absence of regret.

Absence of regret was articulated in 97.5 percent of participants. Parents valued the baby as a part of their family and had opportunities to love, hold, meet, and cherish their child. Participants treasured the time together before and after the birth. Although emotionally difficult, parents articulated an empowering, transformative experience that lingers over time.

INTRODUCTION

Advances in prenatal screening and diagnostics enable providers to identify life-limiting fetal conditions (LLFC) and make recommendations for care. Data indicate that the leading cause of infant death in the United States is congenital malformations that can be lethal or severely shorten infant life-span.¹ Despite technological advancements, prognostic uncertainty is a reality, and in some cases infants live longer than expected.² Until recently women were offered a limited number of options, typically termination of pregnancy or infant admission for intensive care; however, expectant obstetric management and the growth of perinatal palliative care (PPC)—the option to continue the pregnancy and receive interdisciplinary support during pregnancy, birth, and postnatally—have been formally recognized, and these options are now included when careproviders offer counseling to parents.³

Charlotte Wool, PhD, RN, is an Associate Professor at York College of Pennsylvania in York, Pennsylvania. cwool@ycp.edu

Rana Limbo, PhD, RN, CPLC, FAAN, is Director Emeritus, Resolve Through Sharing, Gunderson Medical Foundation, in La Crosse, Wisconsin.

Erin M. Denney-Koelsch, MD, FAAHPM, is an Assistant Professor of Medicine and Pediatrics at the University of Rochester Medical Center in Rochester, New York.

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Perinatal loss is an especially sensitive and sorrowful topic. According to a meta-analysis of studies about perinatal palliative care and perinatal hospice published from 1995 to July 2012, between 37 percent and 85 percent of parents opt to continue a pregnancy affected by an LLFC.⁴ As parents anticipate the shortened life-span of their infant, careproviders need to ensure that their encounters with parents do not increase the parents' distress and suffering. Parents who continue a pregnancy report the desire to "have no regrets" and wish to be supported by careproviders.⁵ Research confirms that parents are more satisfied when quality metrics, such as compassion, consistent care, and emotional support, are rendered.⁶ Understanding the absence or presence of regret in parents who continue a pregnancy with an LLFC will provide additional and important data that careproviders can use when counseling parents.

LITERATURE REVIEW

Making a decision about continuing a pregnancy through the lens of an LLFC is a heart-wrenching decision. Decisions are complex and multifactorial, and clinicians and researchers acknowledge that perinatal loss is a traumatic event that can result in emotional devastation.⁷ Still, the concept of post-traumatic growth has received some attention in the perinatal literature and is worthy of examination as parents must live on after making such complicated, nuanced decisions.⁸ To make the decisions that are best for them, patients need nonjudgmental counseling about options, with the opportunity to voice concerns and ask questions, which may lead to more realistic expectations of outcomes, present an opportunity to examine personal values, and reduce uncertainty or decisional conflict.⁹ If, in retrospect, a parent views a decision with regret, there may be adverse psychological implications. The idea that a decision may result in a protracted period of regret is concerning and, therefore, deserves careful study. Self-blame, a concept often associated with regret, has a negative impact on adaptation following the death of a baby during or soon after the birth.¹⁰

Decision regret has been presented in the literature from different perspectives. Defined as the measurement of distress or remorse after making a healthcare decision, decision regret is considered an undesirable outcome and best avoided when possible.¹¹ Several theorists have attempted to bring clarity to the concept of decision regret. One theory of decision regret includes two core components, the first is associated with self-recrimination or self-

blame about having made a poor decision; another identifies that individuals may experience regret when they have knowledge that a different choice may have resulted in a better outcome.¹²

From an alternative perspective, the wish to avoid regret may play a part in individual choices. In fact, one decision-making theory suggests that decisions may be cognitively processed so as to reduce feelings of regret after the decision and its consequences are complete, especially if the outcome is expected to be less than ideal.¹³ In other words, individuals can anticipate regret, and this fact may influence how a decision is processed and eventually reached. This is especially profound in the context of anticipated perinatal loss, when making a decision—or series of decisions—is an emotionally intense experience with far-reaching, potentially life-long impact. We postulated that parental-fetal attachment and a desire for parental caregiving, that is, nurturing, protecting, and socializing,¹⁴ may contribute to a choice to continue the pregnancy and a wish to avoid regret.¹⁵ Some—or perhaps many—people assume that ending a pregnancy shortly after a diagnosis of an LLFC would subsequently relieve regret and lessen the grief parents anticipate from carrying a baby with severe problems. Data from this study and others suggest that more profound regret comes from failure to spend as much time with their child as they would like, even during pregnancy.¹⁶ Nurturing, protecting, and socializing are not reserved for infants who live only outside their mother's uterus. Instead, parents who choose to continue the pregnancy find joy and gratitude in time spent with their child. Researchers in the perinatal hospice field identify one aspect of caregiving as a thoughtful process of saying good-bye to a much-loved offspring, described as "final acts of caregiving."¹⁷

GAP IN KNOWLEDGE AND STUDY PURPOSE

As the evidence base for PPC grows, it is important for careproviders to understand whether parents who continue a pregnancy that is affected by an LLFC experience feel regret, and in what context. New knowledge about the presence or absence of regret will allow obstetric and neonatal careproviders to align counseling information with data and take a more pro-active role in providing decisional support.

Participants in the study responded to the following question: "Do you have any regrets about your decision to continue the pregnancy?" with a "yes" or "no" answer, and were invited to provide

comments. The purpose of this study is to fill a gap in our understanding of parental experiences after they have had time to live with their decision to continue a pregnancy affected by an LLFC and have had an opportunity to reflect on it.

METHODS

Data were retrieved from a cross-sectional study using the Quality of Perinatal Palliative Care and Parental Satisfaction Instrument.¹⁸ A secondary data analysis of qualitative data from the *decision regret* item was undertaken using the lead author's original database to answer a new research question. The original study was conducted in February 2015 over four weeks. Participants were parents ($N = 405$) who experienced a life-limiting prenatal diagnosis and opted to continue their pregnancy. Infants' diagnoses included Trisomy 18 (53 percent), anencephaly (30 percent), and other conditions (17.2 percent). Participants were mostly White (90 percent) and were from Australia, Canada, the United Kingdom, and the United States. Parents reflected retrospectively on their experiences. At the time of the survey, death of the infant had occurred within five years (61.5 percent), from six to 10 years (25 percent), or after 10 years (13 percent).¹⁹ An online web-based platform was used, and data about quality indicators, parental satisfaction, parents' demographics, infants' characteristics, and additional open-ended questions were posed. The item targeting the concept of *decision regret* was the final item on the survey and invited participants to reflect on their decision to continue the pregnancy. Of the 405 participants, 402 (99 percent) responded quantitatively to the item, and 121 (30 percent) responded qualitatively to the item using an open-ended text box. The study was approved by the York College of Pennsylvania Institutional Review Board.

Authors used the method *dimensional analysis* (DA) to identify context, conditions, and consequences of the absence or presence of decision regret. Dimensional analysis is a method of analyzing qualitative data that grew out of Leonard Schatzman's work with the grounded theorist, Anselm Strauss, and through his work with graduate students who needed an explicit explanation for analysis when using grounded theory methodology.²⁰ One of the unique features of DA is its effectiveness in describing common, everyday experiences, which Schatzman calls "natural analysis."²¹ His point refers to the usefulness of DA for both research analysis and reflection on everyday, usual events, decisions, or happenings. In the case of the

data on which this article is based, the "everyday experience" is reflection on a past decision, albeit during a most stressful and difficult time in the life of a parent. DA provides the framework for answering the question "What all is involved here?" or "What is the big picture?" In our case, Schatzman's model for DA includes analysis of the central unifying concept embedded in the question "Do you have any regrets about continuing the pregnancy?"

DA has been used by numerous researchers as a way of bringing together natural analysis and theory development.²² First identified as a method for developing grounded theory, DA is also a robust method for coding existing data, an appealing choice for a study such as this one, in which participants had already written a brief narrative about regret.²³ DA met the "good fit" criteria for data in which participants identified their relationships as a central issue.

We identified an overarching central issue of regret from analysis of the data. From there, we moved to the next level to bring clarity and understanding to participants' responses regarding the absence or presence of regret. We examined three dimensions that stemmed from the central issue, including:

1. How does the context apply to the central issue,
2. What are the conditions upon which the central issue is understood, and
3. What are the consequences that result from the central issue.²⁴

Initially, our data set was read independently by the authors. Guided by DA, the three authors together organized the data into three dimensions of context, conditions, and consequences (see figure 1). DA is designed to be a close approximation of the participants' experience (their reality) and is ideal when one is looking for the saturation of a specific category or variable. Identifying context, conditions, and consequences moves away from thematic analysis and focuses on interrelationships among the three dimensions. The report of our findings supports the interrelationship detailed in figure 1.

RESULTS

This section will explore the central issue (regret) embedded within the research question, "Do you have any regrets about continuing the pregnancy?" The primary finding was "the absence of regret." More than 400 ($n = 402$) participants answered the quantitative item "Do you have any regrets about your decision to continue the pregnancy?" by checking a "yes" or "no" box. Of those

402 responses, 97.5 percent ($n = 392$) said they did not have regrets; 2.5 percent ($n = 10$) said they did. Participants clearly represented “absence of regret” as the central issue (see figure 1).

Of the 402 participants, 12 (30 percent) provided qualitative feedback on this item, three of whom made statements about their regret (compared with 118 who wrote about the absence of regret). The following were contained within the statements of the three participants who wrote about regret:

1. One participant regretted not being strong enough to “fight for my daughter’s life,”
2. Another hoped that her baby did not suffer, and
3. The third regretted that she had not said goodbye to her daughter “on my own terms.” This mother further elaborated by clarifying that she felt forced to follow state guidelines rather than her own “medical decisions.”

Because so few commented on having regret, DA was not possible for those comments. The rest of the analysis reports on the 97.5 percent of participants who did not experience regret for continuing the pregnancy.

Contextual Factors

Context is an important element of DA to make sense of qualitative data.²⁵ In the data from this study, participants identified the context for “absence of regret” by describing *relationship* as central (see figure 1). Participants acknowledged themselves as parents to their baby and took on the various roles of parenthood.

Acknowledging themselves as parents. Four select examples from our data demonstrated how participants recognized themselves as parents. Participants talked about the fetus, newborn, or infant in relational terms, such as “son” or “daughter.” Frequently they referred to their baby by name and themselves as parent: “I am her mother” or “I was just being the momma I knew to be.” Some parents also spoke in even broader terms of “family” and acknowledging the baby “as much a part of our family as our other children.”

Parental roles. Roles included advocacy, responsibility, and decision maker. Participants explained *advocacy* using simple statements such as “I wish I could have kept my daughter safe inside me forever” and “I did everything I could to give him a chance.” *Responsibility*, on the other hand, was to “ensure comfort,” using words such as “She was in my arms when she left this world and she was safe and comfortable. That was all I could ask; for her to not suffer.” Another parent wrote that she wished to “avoid

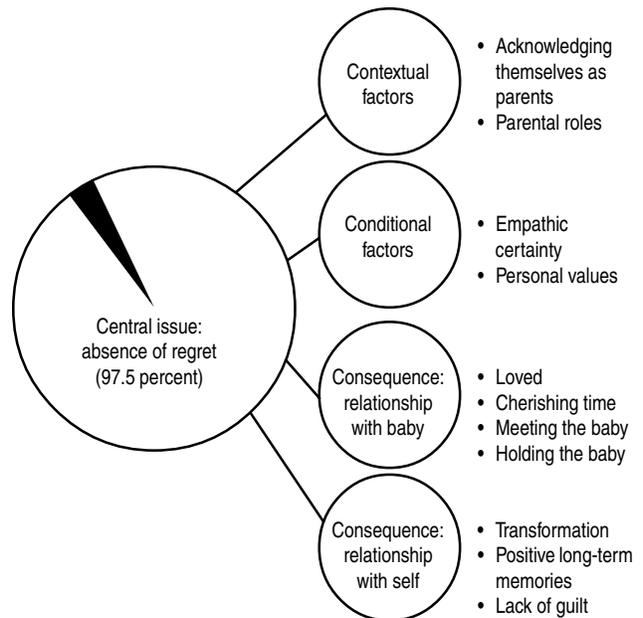
infant pain and suffering,” and yet another noted that protecting the twin sibling was a critical part of her parental role. In relation to a *making a decision* to continue or terminate the pregnancy, one participant stated, this “was the hardest decision I’ve ever made.”

Conditional Factors

A second dimension of analyzing the participants’ data includes conditional factors or conditions. Participants identified two primary conditions in stating that they had no regrets, which include emphatic certainty and personal values (see figure 1).

Emphatic certainty. The authors were impressed with the show of strong feelings and emotions in the category of *emphatic certainty*, made possible through the handwritten comments made as an answer or response to a question. The participants’ written words illustrate how powerful their responses were. Some participants used uppercase letters to emphasize the absence of regret, for example, “NO REGRETS” and “If I had to relive this situation I would NOT do a single thing differently!!” In addition to emphasizing the negative with using both “none” and “no,” this parent used 30 exclamation points to separate the two words. Many parents used the single word “never” in response to the ques-

FIGURE 1. Parental absence of regret in continuing pregnancy with a life-limiting fetal condition: factors from dimensional analysis



tion about regret, emphasizing their strong sense of certainty.

Personal values. Parents referred to their *personal values*, including the sanctity of life, a higher power, and an emotion linking parent and child. Statements such as “Every life is precious,” “It was God’s plan and purpose,” and “I love my girl” reflected parents’ spiritual and moral perspectives on the meaning of the experience.

Consequences

Schatzman defined conditions as being linked through accompanying *actions* or *processes* with consequences.²⁶ Both the context and the conditional factors ultimately lead to an outcome. Our participants expressed several consequences related to the concept of *regret*. Two clear pathways emerged that stemmed from the context of relationships. Choosing to continue the pregnancy resulted in opportunities to be in relationship with the baby and a personal reflection of emotional feelings related to self (see figure 1).

Relationship with the baby. Mothers identified their relationship with their baby as having four major dimensions:

1. *Love:* “All my son knew was love.” “We are rich in love because of her.”
2. *Cherishing time:* “We would not trade those six hours for anything in the world.” “I will always cherish the time I had with her” [during pregnancy and after].
3. *Meeting:* “My family was able to be present when she was born and everyone got to meet her and hold her while she was alive.”
4. *Holding:* “I got to hold my baby for an hour . . . no regrets.” “I got the chance to see her, hold her, and honor her sweet life.”

Relationship with self. Growth and transformation have been suggested as potential consequences of perinatal loss.²⁷ Mothers in this study described growth and transformation as consequences that involved relationship with self. They reported that having no regret for their pregnancy decision affected them in three ways; that their experience was:

1. Transformative,
2. Their long-term reflections on the experience were positive, and
3. Their decision contributed to the healing process and prevented feelings of guilt.

Growth and transformation. Examples of how parents framed transformation as a consequence of not having regret included:

1. Acknowledgment of personal learning and growth, a process that shaped and changed them, the opportunity to heal, and
2. Profound effects on their family’s faith and relationships.

These outcomes lasted over time. Some examples of transformation include the following. “The experience has helped form who I am today, who my husband is today. We learned and grew from the experience.” Another parent expressed it this way: “This became perhaps the most profoundly positive experience our family has ever had. I think nothing else has ever strengthened our faith or drawn us closer together.” Mothers also reported that “He changed me forever” and “Never [did she have regrets]! It was so healing to have met her.”

Positive long-term memories. Some participants in our study experienced loss within a year of taking the survey while others reflected on an experience that occurred more than 10 years earlier. The idea of “long-term,” noted also in the explanation of transformation, is evident as parents discussed their memories. “I have memories that has [sic] carried me through,” “I will love her until the day I die,” and “Thankful every day that we decided to continue,” all exemplify how strength, love, and gratitude can come from one of life’s greatest tragedies: the death of one’s child.

Lack of guilt. The consequence of “lack of guilt” was expressed in numerous ways by participants. One said, “I think it made the grieving period ‘better,’ I mean it is easier to say good-bye to someone you know and have seen.” Another affirmed that the experience “Left me with no questions of ‘What if.’ ” One parent was so pleased not to have missed out on “15 beautiful days with our baby.” Concerns about termination were occasionally but infrequently mentioned for why parents chose to continue the pregnancy: “I cannot imagine the guilt and grief I would still carry had I aborted the pregnancy.” Finally, this quotation summarizes the main finding of the absence of regret: “If I had to relive this situation I would NOT do a single thing differently!!”

DISCUSSION

Most strikingly, our data indicate an overwhelming, emphatic, and almost unanimous response indicating an absence of regret in parents who continued a pregnancy with an LLFC. The participants described the absence of regret with remarkable, emphatic certainty. Parents in our study nearly all felt that they had made the right choice for themselves

and their family, based on their personal values, and showed an absence of post-decisional regret, guilt, or self-blame. Those inexperienced with families who experience an LLFC may find it unusual that continuing a pregnancy likely to result in the death of the baby can produce positive consequences for parents and families, but this has been found in other works also.²⁸ The positive experiences our participants describe affirm theoretical underpinnings that link decision making and outcomes with a lack of self-recrimination or regret. Parents expressed that despite the distressing life event, the best possible outcome was achieved. Parents had an opportunity to meet and love their baby and, in many cases, participants described positive transformative experiences consistent with Beth P. Black and Patricia Moyle Wright.²⁹

Posttraumatic growth (PTG) is a process that occurs in response to suffering.³⁰ The authors noted that the concept has its roots in theories of change, specifically in response to traumatic events that change one's attitudes, meanings, and assumptions of what life is and offers. Significant to PTG in those who experience the death of a baby is that the growth may be private and not noticeable by others, or it may be demonstrated on a continuum to obvious growth, change, and transformation that occur when the growth has social consequences (for example, the design and organization of a remembrance walk named in honor of the baby who died). The authors also noted an important paradox in understanding the interlocking aspects of trauma and growth: The distress from the first is a companion to the positive change experienced and/or noticed with the second. To better understand the structure of PTG, researchers developed a Posttraumatic Growth Inventory (PTGI), which includes five dimensions gleaned from a study of 926 participants.³¹ The dimensions included relating to others, new possibilities, personal strength, spiritual change, and appreciation of life.

As noted by Beck and Watson, "only a handful of studies have been conducted on perinatal post-traumatic growth."³² Their study of 15 women who self-identified as having had a traumatic birth identified four factors of growth, each of which could be linked to one of the five dimensions identified by the PTGI. The women opened themselves up to a new present (new possibilities), were more open and transparent about themselves with others (relating to others, appreciation of life), increased spiritual understandings related to self (spiritual change), and forging new paths personally and professionally (personal strength).

A study of 15 women and 11 of their male partners whose baby had an LLFC used the PTGI to demonstrate that the earliest and most enduring change occurred in relating to others.³³ Participants described positive changes in varying ways. One father/husband said, "We cried the whole way home [after the diagnosis]. But a part of me was sad to see [my wife] so distraught . . . [it] just broke my heart."³⁴ Another participant, a mother, spoke of becoming more compassionate toward strangers: ". . . that felt really good to be an encourager to someone else: to have something positive come out of these feelings and this experience."³⁵

This study confirms prior research that parents' overall goal in a pregnancy with an LLFC is to have "no regrets."³⁶ Parental relationship with the fetus/baby and their desire to be good parents may explain the overwhelming driving force for their decision making. Parents who choose to continue their pregnancies after LLFC displayed "prenatal parenting"³⁷ and wanted their baby to be thought of and treated as a person.³⁸ While anticipatory grief is a reality for all parents continuing an affected pregnancy, palliative careproviders are well positioned to support parents throughout their journey in an effort to minimize potential harm and maximize positive memories and experiences.³⁹

A large body of literature suggests that denial and avoidance of death and grief can have harmful effects. Denial is a defense mechanism described by Freud to unconsciously protect a person from the anxiety aroused by unacceptable thoughts or feelings.⁴⁰ While it is possible that some of the parents who confirmed feeling no regrets were "in denial," the emphatic certainty with which they affirmed their lack of regret and their nearly uniform responses contradict this idea. The lack of regret and prolific expressions of positive feelings after an extended period of time also fits with the authors' clinical experience that parents who choose to continue a pregnancy with an LLFC are not in denial or avoiding death. The parents are living out their dreams of being caregivers for their child in the best way possible, given the circumstances.

Parents' words reflect positive changes that endured over time through relationships, memories, and emotions. For example, the memory of holding their baby, an experience that ended in a relatively short time, was something the parents carried with them, remaining important enough to share with the research team many years after it happened.

Their ability to have time to be a parent to their child and spend time with their baby was meaningful. The concepts of advocacy, responsibility to en-

sure comfort, and making the best decisions are all part of caregiving, consistent with John Bowlby's theoretical framework,⁴¹ in which caregiving is reciprocal to attachment, and parents have goals in relating to their child.⁴² Caregiving goals include nurturing, protecting, and socializing the baby, highlighting the parents' relationship with the baby and the baby's relationship with others (for example, showing an ultrasound photo with pride). Nurturing their child is a common parental caregiving goal.⁴³ Parents in this study described looking forward to meeting, holding, and cherishing time together, suggesting that caregiving goals could affect the decision to continue the pregnancy without regret.

Presence of Regret

While 10 parents indicated the presence of regret, only three of them provided qualitative responses, making it impossible to say in a transferable way why those who had regret felt that way. One participant raised the concern of infants' suffering. Parents in other studies have also voiced this concern.⁴⁴ A cornerstone of PPC includes anticipating and addressing this concern with parents at various points in the pregnancy journey, and especially during the decision-making process. To date, there is no evidence to suggest that LLFCs cause suffering for the fetus during pregnancy, and parents should be given this information as a part of counseling services. Further, to avoid any potential suffering after the birth, parents should be invited to co-create a treatment plan for their infant that recognizes the importance of careful assessment and treatments.⁴⁵ Treatment plans should also address comfort strategies that assess infants' pain and suffering and address them. Evidence-based interventions include both pharmacological pain and symptom management, as well as nonpharmacological approaches, including bonding, holding, skin-to-skin care, suckling, massaging, cuddling, and rocking.⁴⁶ Further, treatment plans should support, as appropriate, comfort measures for infants that address relieving hunger or thirst and maintaining body temperature.⁴⁷ When parents desire life-sustaining treatments that carry a potential for pain or distress post-birth, excellent palliative care can help minimize any pain and suffering that might accompany those treatments.

CLINICAL IMPLICATIONS

This work informs all interdisciplinary health-care team members who work with parents facing

LLFCs—including nurses and physicians in obstetrics, neonatology, and perinatal palliative care—by demonstrating with data a profound lack of regret for the vast majority of parents who continue their pregnancy. Decision regret may be modified through collaborative decision making between care providers and parents as the best available scientific data are presented and coupled with parents' preferences and values.⁴⁸ Counseling, which traditionally includes information about termination, should also include apprising women of a palliative care option that includes data about the emotional and psychological aftermath of those respective decisions.

Women are compelled to weigh and decide on a course of action that remains in their personal history forever. Caroline Lafarge and colleagues found that women who terminate a pregnancy and indicate that they are unsure they would make the same decision again have difficulty coping and report increased despair and grief.⁴⁹ In the same study, self-blame was one variable involved in positively predicting active grief, difficulty coping, despair, and general grief. When women opt for termination for fetal anomalies (TFAs), the nature of such a choice is voluntary. Suddenly, a happily anticipated life event (birth of a child) is coupled with a life-limiting diagnosis, which creates an existential crisis both for and against something both wanted and not wanted.⁵⁰ Judith L.M. McCoyd's research addresses the intense and unbearable stress felt during the decision-making process by women who opt for TFA.⁵¹ McCoyd posits, "The responsibility for decision-making complicates and seems to intensify [this] grief."⁵² Perhaps the voluntary nature of TFA accounts for some of its psychological aftermath. In addition, McCoyd identifies a confluence of other factors that may contribute to psychological outcomes, such as the stigma of termination, a society unwilling or unable to offer support and advocacy, fear of judgment from others, the difficulties inherent in the delivery and birth of an infant with a life-limiting condition, and a lack of accessible, streamlined healthcare services from care providers and health insurance organizations.⁵³

After TFA, women have reported negative emotions such as grief, posttraumatic stress, depressive symptoms, anxiety, sadness, and distress.⁵⁴ Over time, the negative effects of TFA subside, although Marijke J. Korenromp and colleagues noted grief reactions that persist years later.⁵⁵ Our study did not examine those who chose to terminate a pregnancy, and we cannot comment on those families' presence or absence of regret. At the same time, we were struck that the adverse psychological outcomes found in

the literature are in contrast with the positive emotions and consequences parents almost unanimously reported in our research.

Clinicians have a responsibility to translate evidence into practice and provide comprehensive information to parents so that they can make informed decisions. Maria-Margarita Becerra-Pérez and colleagues examined participants' satisfaction with the information they received; low satisfaction with provided information is associated with decision regret.⁵⁶ Many institutions do not have PPC, and even those that do have a low number of PPC referrals,⁵⁷ which represents a formidable barrier for parents who may benefit from hearing about the option to continue a pregnancy and receive supportive services offered by PPC teams. Leaders in PPC programs in the U.S. stand ready to provide exceptional family-centered, individualized care and support to parents.⁵⁸ Clinical pathways and position papers are available to inform practice, and the Perinatal Hospice and Palliative Care internet site provides a convenient avenue to find and contact available PPC programs (*PerinatalHospice.org*).⁵⁹

LIMITATIONS

Our study begins to lay a foundation for understanding decision regret in the context of an LLFC. This is a first step in such inquiry through a single, open-ended question. The population was largely White and English speaking, limiting the transferability to minority and other cultural groups. There is no literature to suggest that LLFC in other cultural settings is a profoundly different experience, making this less likely of a concern. The possibility of parental recall bias is inherent in the study design, although research suggests that women have enduring and accurate memories of their birth experiences.⁶⁰ So few parents indicated having regret that their qualitative responses were quite limited, and we cannot draw any conclusions from them.

Social desirability bias is another possible limitation, if parents felt it was not socially appropriate to express regret about birthing a child. We concluded that social desirability was a minor concern, given the findings of "emphatic certainty" with which they answered the qualitative portion on their lack of regret.

Our study did not include a valid measurement tool specifically targeting regret, although such a tool exists and has been used with a variety of populations.⁶¹ Use of the Decision Regret Scale may have led to a deeper understanding of the concept of regret and provided a more in depth examination.

Qualitative research with focus groups or interviews would also have expanded upon parental perspectives and experiences.

The strengths of the study include the use of DA and a research team that included two nurse scientists with perinatal loss expertise and a palliative care physician. From these data, perinatal clinicians will be able to counsel patients that continuing a pregnancy with an LLFC is usually not viewed with regret by a vast majority of parents who opt to continue. This study confirms that an overwhelming percentage of parents had no regrets about continuing a pregnancy when the baby has an LLFC, and in many cases had a meaningful, loving, precious time with their baby. These meaningful moments can inform the counseling practices of all clinicians who care for these families and the experience of the families themselves. As one participant said, "[I was] able to hold and kiss her and sing to her. I will always cherish those moments." Those tender words lead the reader to conclude that she "would do it all over again."

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Perspectives

The Mission of Safety Net Hospitals: Charity or Equity?

Thea James

ABSTRACT

The traditional mission of safety net hospitals has been charity, providing the best healthcare for all individuals no matter their ability to pay. The focus has been on vulnerable populations that are low-income, uninsured, and other upstream circumstances that manifest downstream as poor health, poor health outcomes, and repeated high-cost interventions that fail to break cycles of perpetual health instability. Safety net hospitals are committed to serving their populations, even if only temporarily, through provision of subsidies and filling gaps that exist in patients' lives. These interventions do not lead to the elimination of gaps, hence cyclical health instability persists. It is a new day in healthcare and what it means for people to be well. The focus is on improving health outcomes by addressing root causes of health instability such as unstable housing, income, education, and access to affordable healthy foods. This gives us pause to reflect on the traditional mission of safety net hospitals and the impact of charity in isolation. Are safety net hospitals missing an opportunity to mitigate and eliminate perpetual health instability? Can they shift the paradigm of healthcare for vulnerable populations to alter their quality-of-life course? To move forward, safety net hospitals have to change their mind set and existing narratives about what is possible for vulnerable populations to achieve. These historic giants in healthcare have an opportunity to use their assets and employ a methodology of

disruption and innovation to shift the mission of safety net healthcare from charity to equity.

Three years ago I had the privilege to become the first Vice President of Mission in a nonreligious, safety-net, academic medical center. Unknown to me, Vice President of Mission is traditionally a role found in faith-based healthcare organizations. Prior to entering the C-suite, my previous 24 years were spent as a practicing emergency medicine physician at my present medical center, where a majority of the patients represent underserved populations and are socioeconomically living below the federal poverty line. Our patients and their families taught me everything I know about what they say they need to be well and to thrive. Throughout the years my experiences partnering with them has shaped my perspective on the notion of "mission." Although my role was new to me and to our organization, I felt I had been preparing for it for years and somehow felt a natural connection to it.

I moved into a quiet new office located away from the constant chatter, action, multi-tasking, and controlled chaos of the emergency department. I thought about how fortunate I was to reach this point in my career and have a new opportunity to learn, to be challenged, to make mistakes, and to join the team of leaders who ran our healthcare system. My hope and goal was to be able to contribute and add value to our organization, our partners, communities we serve, our patients, and my colleagues. I en-

Thea James, MD, is an Associate Professor of Emergency Medicine at Boston University School of Medicine and is Vice President of Mission and Associate Chief Medical Officer at Boston Medical Center in Boston, Massachusetts. Thea.James@bmc.org
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visioned us shifting into another gear, moving beyond the *status quo* approach of providing healthcare for vulnerable populations—charity. I knew I saw things through an alternative lens. I also knew any vision would have to be clearly communicated as something that would contribute value to our bottom line.

From my view of my new role, I questioned what mission meant and wondered whether we were meeting our pledge. Having spent my entire career in a safety-net healthcare system I questioned the practice of *charity* and its true impact on vulnerable populations, especially as it relates to our mission. I asked myself whether charity would ever enable our patients to step out of the “line of need” and move to independence and thriving—versus barely surviving. I questioned how charity might be influencing where we set the bar for our mission, for our healthcare outcomes, and our achievement goals. I questioned whether our existing healthcare intervention model for a vulnerable patient population might cause us to inadvertently miss new opportunities to enhance financial performance. Could we move beyond the *status quo* of how healthcare systems care for vulnerable populations? Finally, I wondered whether we could shift our entire healthcare delivery paradigm upstream from charity to equity?¹ That shift would be a challenge; the greatest challenge would be changing mind set about what is possible for vulnerable populations and for us as a healthcare organization to achieve. We are a nimble, creative, and bold organization, but the narrative about what is possible for vulnerable populations to achieve is an amalgamation of hard-wired assumptions.

Visitors touring our healthcare campus often tell us that, unsolicited, employees throughout our campus say they work here because of the mission. There are other employees who, when asked in passing, “How are you doing?” respond with “Saving lives.” I assume that for my colleagues the meaning of mission is subjective, but their individual interpretations are probably more similar than different. I think what most employees mean is they have chosen to work in a healthcare system where the majority of patients are overwhelmingly socio-economically vulnerable, ethnically diverse, minorities, and many are immigrants; they want to help. My colleagues are committed to serving this population in the best way they know how, even if only temporarily filling existing gaps in the lives of patients. It is certainly understandable given our healthcare system’s rich history.

In 1864 our organization opened its doors as the first public hospital established in the United States. The hospital was “intended for the use and comfort of poor patients, to whom medical care will be provided at the expense of the city, and . . . to provide accommodations and medical treatment to others, who do not wish to be regarded as dependent on public charity.” Today, that mission has not changed. But paying attention while working in the emergency department provided me with a glimpse into human nature, the human condition, and all of what constitutes life. It taught me to listen and to learn what matters to people. I learned that our treatment plans cannot compete with people having to prioritize the basic necessities of survival over their health—no matter how much we “help” them. As humans with limited resources, when patients have to make hard choices between feeding a family, maintaining unstable shelter, keeping the lights on, and purchasing a prescription, health and healthcare will always be ranked secondary to survival. We have to be mindful, intelligent, and informed to avoid the mistake of passing judgment on the downstream medical consequences of patients’ lack of options.

It is a new day in healthcare and what it means for people to be well. We have to be thoughtful and decide: Are we going to anchor vulnerable populations with opportunities to thrive? Or will we use charity and anchor them in place with no way out? “Anchoring” is a double entendre.

Today the medical approach to wellness is not repeatedly treating acute and chronic unstable disease in isolation, because these are downstream consequences of root causes upstream like housing, income, education, and healthy affordable food. Our mission should be targeted there, upstream, to mitigate and eliminate those gaps with interventions that alter the quality of our patients’ life course.² For example, going forward we will not summarily provide access to temporary food subsidies to address food insecurity. Our operations intervention model will include access to living-wage-paying employment to eliminate the gap. To sustain our interventions we have to go farther upstream with our mission outside our hospital walls.³ We are developing partnerships with multisector industries and other medical centers to leverage our collective resources to disrupt structural barriers to thriving and stable health that exist in communities.⁴ We aim to transform communities by creating inclusive stable economic solutions that lead to healthy and vibrant communities.⁵

CONCLUSION

Understanding the root causes of chronic health instability and socioeconomic vulnerability is necessary to eliminate them. From my perspective this is our mission. We need critical insight to eliminate drivers of non-adherence, cyclical poor health outcomes, excessive healthcare utilization, and high costs. Comprehension of the roots of socioeconomic vulnerability and the structural barriers that create it is an invaluable complement to compassion. This is especially true when cynicism and compassion fatigue sometimes overwhelm best practices. Humans respond to kindness and sincerity, even in their worst state. In fact their worst state is our greatest opportunity to alter their perspective on what is possible. I begin by asking patients: "What would it take for this to never happen again?" Their responses are most often not insurmountable and are in fact logical and reasonable.

In my new role as VP of Mission I imagined an opportunity to re-examine our mission. I know we are nimble, creative, and bold and can shift the mission paradigm from charity to equity, and gradually integrate it into our business model to have social impact, a business impact, and to show a return on our investment. I thought we should seize the moment of a national focus on the determinants of health and leverage accompanying funding supports to create infrastructure to achieve a higher mission that is mutually beneficial to our patients, surrounding communities, and our healthcare system. We have an opportunity to shift from charity to equity, a healthcare paradigm shift for the long term. I will describe our work and specific programs in more detail in a future article in *The Journal of Clinical Ethics*.

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Scribes, Electronic Health Records, and the Expectation of Confidentiality

Paul M. Wangenheim

ABSTRACT

Electronic health record (EHRs) have largely replaced obsolete paper medical charts. This replacement has produced an increased demand on physicians' time and has compromised efficiency. In an attempt to overcome this perceived obstacle to productivity, physicians turned to medical scribes to perform the work required by EHRs. In doing so, they have introduced an uninvited participant in the physician-patient relationship and compromised patients' confidentiality. Scribes may be a successful work around for physicians frustrated by EHRs, but patients' confidentiality should not be sacrificed in the process.

INTRODUCTION

More than 30 years ago Mark Siegler, MD, asserted that confidentiality in medicine was a decried concept. He cited a case of a patient admitted for cholecystectomy and discovered that nearly 100 staff, students, and hospital personnel had access to the patient's medical chart. Despite reassurances that all parties had professional justifications to see his medical records, the patient felt his confidentiality was breached. In his essay Siegler proposed parti-

tioning the chart so that clinical information would be separated from financial information and access would be limited to legitimate inquirers on a "need to know basis."¹

Today EHRs have largely replaced obsolete paper charts. Access to EHRs is available to multiple simultaneous viewers. Confidential information shared between patients and physicians may be compromised by this open access to EHRs. Beauchamp and Childress explain that confidentiality is a "subset of informational privacy" and prevents "redisclosure of information originally disclosed in a confidential relationship."² Confidentiality is breached when private medical information is shared without consent and widespread access to EHRs potentially threatens patients' privacy.

THE ELECTRONIC HEALTH RECORD

In 1997 the Institute of Medicine called for the implementation of computer-based medical records. The Committee on Improving the Patient Record concluded that the "computerized patient record, in short, is an essential technology for health care" and promised to improve productivity, quality of care, job satisfaction, and customer satisfaction.³ Rapid proliferation of EHRs followed the Health Information Technology for Economic and Clinical Health Act (HITECH) of 2009. This legislation provided incentives for both office-based physicians

Paul M. Wangenheim, MD, is a Physician in practice at Southern Vermont Health in Manchester Center, Vermont; when this article was written he was Chair of Bioethics at Saint Barnabas Medical Center in Livingston, New Jersey. *Paul.Wangenheim@svhealth.org*
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and hospitals to adopt EHR systems. The program was successful. In 2001, only 18 percent of office-based physician used some form of EHR, and by 2013 that figure grew to 78 percent.⁴

Similar exponential growth occurred in the hospital arena. Nonfederal acute care hospitals in the United States that provide care to Medicare and Medicaid patients and meet nine objectives and measures set forth by the Centers for Medicare and Medicaid Services (CMS) avoid penalties and reductions in payments by adopting EHRs. In 2008 only 9.4 percent of these hospitals had basic EHR systems compared to 75.5 percent in 2014.⁵

Despite the potential for improvements in patients' safety and the quality of care, the widespread implementation of EHRs have had a negative impact on physicians. The additional time required to navigate EHRs reduces productivity, income, and job satisfaction.⁶ In an effort to work around the demands of EHRs, physicians have created solutions that compromise patients' confidentiality.

PHYSICIANS, THE EHR, AND SCRIBES

A recurring complaint among physicians utilizing EHRs is the amount of time spent on the multiple tasks required for their meaningful use. Typing patients' histories, navigating myriad drop-down menus, entering orders electronically, and managing pharmacy prescriptions all add to the amount of time required per patient. Studies report a growing discontent with the quality of the physician-patient interaction as well as the length of physicians' work week.⁷

One solution for physicians who are burdened by the demands of EHRs is the use of medical scribes. These are unlicensed, unregulated employees who record clinical information on behalf of physicians, freeing them from the time requirements posed by EHRs. Scribes enter EHRs with ease and have full access to patients' medical charts including history, physical exams, labs, and consultations. These notes are then co-signed by the attending physician and entered into the permanent record.

There is a rapidly growing industry of private companies that offer the training and certification of medical scribes. The American College of Medical Scribe Specialists (ACMSS) is a nonprofit organization that provides aptitude testing, documentation of work experience, and pathways to certification for medical scribe specialists (CMSS). The organization has certified more than 5,000 individuals in its CMSS program since 2010.⁸ Regulatory agencies such as the Joint Commission and CMSS

have little to say about scribes, although both agencies emphasize that scribes should not be permitted to enter orders into EHRs.⁹

Critics suggest that scribes are not a solution to poorly designed EHR systems and "the rise of the medical scribe industry should not be a substitute for much-needed EHR innovation and transition to more highly effective and more functionally efficient EHR systems."¹⁰ Physicians have perceived scribes in a positive way, citing increased productivity, efficiency, and revenue.¹¹ Scribes are commonly found in emergency departments, clinics, ambulatory practices, and increasingly alongside inpatient hospitals. Notwithstanding the call for improvements in the inadequacies of EHRs, the scribe industry is likely to continue to grow.

PATIENTS AND SCRIBES

Surveys of patients' reactions to the presence of a scribe are generally neutral or favorable. Questionnaires emphasize the increase in attention, better explanations, and more attentive listening that occurs when scribes assist physicians.¹² There are little qualitative data that explore the comfort level of patients who discuss confidential or sensitive information when a scribe is present. A small survey of behavioral healthcare "consumers" indicated overall satisfaction with physicians' communication when scribes were introduced, but included only one question about patients' comfort.¹³ There are scant data about the potential chilling effect that scribes may have on patients when they discuss highly personal information. Scribes were viewed positively in a survey of primary care practices, but individual survey respondents expressed concerns about "invasive checkups" and sexual information when scribes were present.¹⁴

PATIENT'S EXPECTATIONS AND THE CONCENTRIC RINGS OF CONFIDENTIALITY

It is reasonable to expect physicians and nurses to share confidential information in order to deliver care. Patients' expectations for confidentiality can vary widely. Sankar and colleagues examined patients' views of confidentiality by searching more than 5,000 articles using Medline and Ethiconline. Four key areas were identified: patients' understanding of medical confidentiality, what limits should be placed on sharing information, how confidentiality affects patients, decisions to seek care, and finally how concerns regarding confidentiality influ-

ence patients' willingness to disclose information. This literature review reveals the wide variation in what patients think confidentiality means. Patients generally understand that information will be shared with staff, but express concern that such information will impact their social status in their community. Patients who were surveyed largely objected to the routine release of information to insurance providers, commonly expected that confidential information would be used only as a means to achieve good care, and were less concerned with regulations and compliance issues than they were with the fear that their private matters might become public.¹⁵

Siegler's 1982 *New England Journal of Medicine* article recommended that confidential information be shared on a need-to-know basis. The dissemination of patients' information can be imagined as a series of concentric circles emanating outward from the initial doctor-patient encounter. The innermost circle consists of physicians, nurses, nurse practitioners, and physician assistants, who are the most entitled to privileged information. In teaching hospitals this inner ring would also include house officers, residents, fellows, and medical students. The next circle of caregivers includes social workers, therapists, discharge planners, and case managers. These vital ancillary services require knowledge of personal information in order to provide good care and to fulfill patients' needs. Further from the inner circle are healthcare workers who can carry out their services without knowing intimate details about patients. Transporters, phlebotomists, technicians, nursing assistants, and aides require only minimal healthcare information to perform their duties.

Arguably, medical scribes do not have a justifiable place in the hierarchical rings of healthcare providers. Scribes may accompany physicians during the initial patient interview, taking notes and instructions that will later be entered into EHRs. In other situations the scribes operate remotely. Scribes may access EHRs from a separate location and take verbal instructions from the bedside physician to embellish the EHR template. In either case, scribes share confidential information in order to construct a physician's note in the EHR, and then return it to the physician for a signature before the note is entered into the medical record. Although these services are advantageous for physicians, they are of no benefit to patients.

CONCLUSION

Initially there was great enthusiasm for EHRs and the promise of providing "history-rich notes"

while maintaining "the humanistic elements of the record."¹⁶ Instead, EHRs have become a tool for billing and regulation and a distraction that interferes with the patient-physician relationship. To minimize the impact of EHRs on productivity, revenue, and work hours, physicians turned to scribes as a solution. In doing so they have introduced an uninvited guest into the relationship. Scribes improve physicians' difficulties with EHRs, but at the expense of patients' confidentiality.

When physicians utilize scribes at the bedside, they should be introduced to patients, their role should be clearly explained, and permission should be obtained from patients before proceeding. In the case of scribes who work on charts in remote locations, all identifying information and personal demographics should be redacted from the EHR template in order to maintain patients' privacy. As long as there are inadequacies with EHRs, scribes are likely to continue their growth in the clinical arena. However, the primary goal of every medical encounter is to put patients' interests first; maintaining patients' confidentiality is paramount. Scribes may be a successful work-around for physicians who are frustrated by EHRs, but patients' confidentiality should not be sacrificed in the process.

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