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At the Bedside

When Should Careproviders Deviate from Consensus?

Edmund G. Howe

ABSTRACT

Consensus documents may be extremely helpful. They may, however, also do harm. They may, for example, suggest interventions that are less than optimal, especially when they apply to patients whose situations are at the "outer margins" of their applicability. Yet, even in these instances, clinicians and ethics consultants may still feel pressure to comply with a guideline. Then, we may not do what we think is best for our particular patient because we fear departing from a guideline. In this article I discuss the risks of departing from guidelines and suggest what we can do to overcome those possible risks. I suggest that while guidelines may help, we should continue to put, above all else, tailoring our interventions to our patients' individual needs and wants. With our patients, together, we should decide what to do, notwithstanding what the most applicable guidelines propose.

In this issue of *The Journal of Clinical Ethics* (*JCE*), in "An Argument for Standardized Ethical Directives for Secular Healthcare Services," Abram L. Brummett and Jamie C. Watson "argue for the creation of a concise, nationally endorsed bioethical consensus document on moral issues that are commonly faced in clinical ethics," to be used by clinical ethics consultants when they make recommendations that "circumscribe the range of ethically permissible options in cases of moral conflict or uncertainty."[1] This innovation could benefit patients greatly. Yet there are risks that documents written from consensus may create. For example, a consensus document may be drawn too broadly, or may be misapplied, or may include bias. Put simply, the views of others, of any kind, may

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affect clinicians' decisions, whether in the form of a consensus document or in the form of colleagues' differing opinions. While others' views can be instructive, they may also exert peer pressure, and, in response, clinicians may alter what they would otherwise do. This may be detrimental to patients.

In my introduction to this issue of *JCE,* I will discuss these risks. I will broadly consider documents that are based on consensus, when they function as directives or guidelines that may place pressure on clinicians to follow these directives rather than decide what is best, on their own, for their patients. The consensus-based documents I will consider include instructions such as the law, on one extreme, and the majority opinion of a medical staff at a patient's bedside, on the other. In his seminal work, *Deciding Together: Bioethics and Moral Consensus,* Jonathan Moreno presents the pluses of the ethics consensus documents he describes.[2] I will discuss other aspects of consensus-based ethics directives: how clinicians may apply them and how that may go wrong. I will do this in three sections. In the first section I will discuss the three risks just noted:

1. Clinicians apply a consensus-based directive too broadly, so that an exception to the directive is not made when it should be.
2. Clinicians extend a directive too far and apply it to a case to which it should not be applied.
3. Clinicians write a consensus document that includes bias; for example, a clinician group may reach internal consensus and create a document that is based on its limited consensus that may, consciously or not, disadvantage others.

In the second section of this article, I will consider some of the risks posed by consensus documents that are described in cases published in this issue of *JCE.* One case, presented by Brent M. Kious, Toni Hesse, and Philip L. Baese, involves an adolescent who refused to be vaccinated for COVID-19.[3] Her parents wanted her to be vaccinated, and the law was on their side. In another case, presented by Olivia Silva and colleagues, a 65-year-old patient who had been on dialysis for some time suddenly wanted to stop, and her clinicians had to decide whether she had the capacity to make that decision.[4] The clinicians' decision could have denied the patient her autonomy.

In the third section of this article, I will outline some issues to consider when we must choose between following our colleagues' consensus regarding how best to treat a patient and what we believe will be best for the patient. To do this, I will discuss a neurosurgeon's account of his experiences during and after he carried out a complex, lengthy brain surgery. The neurosurgeon eloquently describes how he chose between doing what he thought his colleagues might advise and what he thought he could and should do. He chose the latter, and describes the emotions that may accompany having to decide between following colleagues' consensus or following one's own individual, even idiosyncratic, views on how best to care for a patient.

FOLLOWING A DIRECTIVE: POSSIBLE GAINS AND RISKS

In this first section I will discuss the risks that following a directive based on clinical ethics consensus may present. I will also consider some of the core gains that may be achieved by following a directive, so that, when I discuss the risks of following a directive, the relative moral weights, pro and con, are balanced and reside in their appropriate context.

Possible Gains

Clinical ethics consensus documents, at their best, may be used by ethics consultants when they are asked to advise clinicians. These documents may address methodology or provide specific guidance. They also may help clinicians determine how strong their reasons should be, should they want to go in a different direction. This last point may require elaboration. When clinicians consider whether they should depart from a consensus document, they should understand what the law would call their "burden"—the degree to which their reasons for departing from a consensus document should prevail. In this legal sense, "burden" refers to *who* must prove *what* for an outcome to prevail. A familiar example is what must be done to prove a defendant's guilt or innocence: a judge or jury has the burden to prove a defendant's guilt, or the defendant is found to be innocent and is set free. In much the same way, when there is ethics consensus regarding how to treat a patient, the burden will be on the clinical ethics consultants or clinicians involved to show that they are justified in not following the consensus

document. Thus, consensus documents can alert these parties to the strength of the arguments they must make to justify their departure from the guidelines.

In the rest of this first section I will make the general argument that the clinical ethics experts who work to create an ethics consensus document, as Brummett and Watson suggest, may have much that is valuable to say and to offer. Consensus guidelines promulgate best practices based on advances in knowledge and evidence.

Here is an example: clinicians, as a group, may have exceptional insight regarding how to help a patient's loved ones when they grieve as the patient is dying or has died. Many will feel guilt and shame that is unwarranted. They may blame themselves after the patient dies because of the feelings they had (or did not have). They may feel shame that they don't feel worse than they do; they may worry they didn't love the patient enough, even though they loved the patient greatly. They may heap shame upon themselves because they felt so badly for so long, or they felt badly as much as they did. They may have been told that it's past the time they should have "gotten over" the death.

Due to experience, clinicians may know better, and we can share our knowledge and experience with patients' loved ones. We have exceptional insight on grieving because we have encountered these situations more than many people have. Thus, when clinical ethics experts gather to formulate guidelines, the guidelines are likely to reflect their exceptional insight.[5]

To return to the point regarding clinicians' possible assistance to loved ones: we may be able to help loved ones when they feel irrational guilt as they grieve. Their feelings may be based on what they themselves believe, or on what they have been told by others. They may feel guilty because of what they *could* have done, regardless of what they actually *did*. There always seems be more that grieving loved ones could have done. But they may not be able to imagine that there could always be more. Clinicians who appreciate their feelings may instruct loved ones so that they don't blame themselves. We may be able to warn loved ones about this beforehand, so that they avoid adding guilty feelings to their feelings of grief.[6]

Practically, consensus documents also help clinicians because we do not have to reinvent optimal ethical practices. These documents, as guidelines—implicitly, at least—allow and anticipate that we may make exceptions to them.

Possible Risks

A consensus document may be too widely applied, overly general, or even biased. Here are examples of each of these.

A Directive May Be Applied Too Widely

Clinicians may follow a consensus document such as an advance directive whenever it could plausibly apply. Doing so may be ideal based on feelings of professional humility; that is, we may be in touch with our own clinical limitations relative to the skills of others. We may regard other clinicians as having capacities beyond our own and thus when we read, for example, an advance directive form, we may defer to the expertise of those who wrote it.

I can identify with this. I am less skilled at treating some patients than others are. On this basis, when clinicians who are more skilled with a particular sort of patient is available, I will refer those patients to them whenever I can. Or we may defer to expert consensus due to fear. We may believe that if we depart too much from expert consensus and go too far, we will be personally more vulnerable and may even fear litigation. Again, I get this. "Going beyond" is, for me, worrisome. I even fret when I tell colleagues that I give patients my home phone. Doing this is easier for me because I see patients only part time. Still, however, I am wary of seeing in my colleagues what I may perceive, rightly or not, to be a critical look. They may see this practice as unwarranted. This question has evoked heated discussion at professional conferences.

In general, while there is a strong case to be made for deferring to consensus documents, a strong case also exists for clinicians to consider departing from a consensus position. A departure may be preferable clinically because the gains from following such documents may be less than the downsides. The benefits of following a consensus document may shrink as actual situations near the outermost margins of the applicability of the document. I will shortly provide an example.

Even finding consensus regarding when to depart from consensus is problematic. Some believe that they should strictly "comply"; others, that they should depart more readily and often. Consensus-based documents may be inherently biased by the moral framework on

which they are built. When I made the suggestion, above, that there is a strong case for clinicians to consider departing from consensus documents in most, if not all, cases, I was disavowing an ethical stance known as rule-based utilitarianism and, in some cases, de-ontologically based consensus statements. According to these stances, a justifiable response and retort might be, "No! Clinicians should follow the same rule or guidance in cases to which the document is meant to apply, so that the best overall result, for the most people, should be achieved!" This strong utilitarian framework would accept that there might be increased harm from following a guidance document for patients who are "at the edge" of the applicability of the document. This increased risk of harm goes against the priority most clinicians traditionally hold and cherish—that we should do the best we can for the patient who is before us.

Rather than seeing directives as absolutely all-inclusive, we might instead see them as being written with the knowledge that there may be exceptions, although these exceptions are not specifically spelled out. This is a point that Moreno continually makes clear. Given this, we should always ask whether, for the patient before us, we should make an exception, because this is what directives almost always implicitly intend. Thus, ideally, we should freshly analyze every patient's situation to discern whether a directive is applicable. We should do this even when we believe departure from consensus should be extremely rare.

An example of when to freshly analyze the applicability of a directive is when patients have dementia and can no longer safely eat or drink; when they eat or drink they can aspirate the food or liquid and take these substances into their lungs, and get a whole bodily infection—sepsis—and, as a result, may die.[7] These patients may aspirate substances because they have forgotten how to swallow when they eat or drink.

Clinicians who are experienced in treating these patients may tell colleagues who are less experienced that they should never feed the patients artificially, including, for example, never surgically inserting a feeding tube into a patient through the abdomen, that is, never perform a percutaneous endoscopic gastrostomy (PEG).[8] These experts and specialists may be most adamant on this point. There have been reports that some clinicians have told patients' family members that if they will not agree to give patients only comfort care—that is, no PEG—the clinicians will deny hospice home care for the patients.[9] Clinicians who have greater experience may express this view as a professional consensus. Such a peer-based guideline differs, of course, from the consensus documents urged by Brummett and Watson, but the likely social pressure such peer-based communication exerts may be similar. Individual clinicians may similarly accede to the views of those with more experience, when they would otherwise want to depart from this advice and tailor their interventions to their patients' idiosyncratic needs and wants.

There are good reasons to counsel against the placement of a PEG. It may lead to earlier death. But such an absolute prohibition from even just one expert or specialist may function as a directive that places great pressure on other clinicians who treat these patients, and this may wholly determine what less-expert clinicians do. The pressure on clinicians increases as the number of their colleagues who advise them increases. There are reports, however, that placement of a PEG may enable some patients with dementia, even if rarely, to live longer. (Of course, eventually their course will still be downhill.) Clinicians who have cared for many of these patients in nursing homes relate that some patients have been kept alive by the placement of a PEG, and that the patients have thrived, as have their family members, for months and even sometimes years.

It is worth noting how this may occur, or, stated more precisely, how patients' loved ones may help make this possible. Researchers in Israel report on loved ones who do what is now called "emotion work."[10] These family careproviders, who care for their elderly, demented loved ones at home, have been able overcome the burdens they encountered in providing care, although at first they reported that they did not believe that would be possible. The researchers report that there is a cultural expectation in Israel that the caregivers will be able provide the care that their elderly family members with dementia need. The researchers report that family caregivers came to believe that they should be able to provide the needed care, and so they tried—and they did. There also is a cultural expectation that family careproviders should try to appear joyous as they provide care, which, in some cases, became a self-fulfilling prophecy. Some became joyous. They transformed. Their

efforts enabled them to find strengths that they didn't know they had.

This report indicates how meaningful, mutual interaction between family caregivers and their loved ones who have dementia is possible, regardless of their illness and the downhill progression their illness will eventually bring about. These accounts show that a transformation by purely psychosocial means is possible. Knowing this, clinicians may decide not to follow a "never place a PEG" directive when they otherwise might. They might respond with shared decision making with the patient and family.[11] The "burden" of making such a decision would then not solely rest on the clinicians.

Taking this approach, to disregard consensus (be it formal or informal consensus) and engage in shared decision making with patients and families also is possible with severely impaired infants and children. There is evidence that clinicians often underestimate the possibility that these children and their parents may, like the loved ones of the elderly patients with dementia described above, have a joyous and meaningful quality of life.[12] Clinicians may tend to underestimate the quality of life of these children and their families because we try to imagine how the children and parents would feel. On the one hand, our imaginings may sometimes be accurate. But some parents may, like the caregivers of the elderly patients with dementia, be able to do "emotion work" and transform themselves and provide a good life for their child and themselves. In any case, in these instances, both children and their parents may do well—and much better than we may be able to imagine.

Such good outcomes are referred to as the "paradox of disability."[13] The cause of this paradoxical result may be our capacity to alter what we and others with us experience, socially, as a result of our interactions.[14]

A Directive May Be Overly Inclusive

There is a risk that a directive may be, often inadvertently, overly inclusive.

Valuing others' cultural beliefs. A well-known example is the emphasis we place on truth-telling that may not be appropriate for people from another culture.[15] As can happen in other situations, there may be consensus among staff that leads to a sort of informal directive that does not respect difference. For example, family members from another culture such as Japan may come into a hospital in the United States with their loved one, take a clinician aside before their loved one has a diagnosis, and ask the clinician not to tell the patient if the patient is dying, but rather to tell just members of the family.[16] This may cause an unprecedented uproar among the staff, that occurs, initially at least, only or mostly behind closed doors. Clinicians may object to honoring the family's request because the staff's ethical priority, in such instances, is to respect the *patient's* autonomy—by informing the patient that the patient is dying (if that is the case) and then asking the patient what the patient prefers to do. Clinicians may believe, too, that if they respect the family's request, they can't adequately treat the patient because they can't provide information to the patient and regularly ask what the patient wants most. This example illustrates that there are different degrees and kinds of guidelines that exert pressure to conform. Given these differences, the criteria for when to depart from guidelines will also differ.

A chief concern this type of conflict can raise, regardless of these differences, is how patients, families, and clinicians can establish and maintain trusting and caring relationships when clinicians stick to and impose their views.[17] I am concerned in every case of ethical conflict that clinicians who take a unilateral stance may undermine their relationships with patients and families. As above, there is evidence that relationships may improve the outcomes of patients with dementia and their caregiving loved ones. Patients' relationships with members of the medical team may determine how well patients do.[18] Clinicians who are aware of the importance of relationships may take the risk of disregarding consensus and decide by themselves, or with the patient and family, how to treat the patient.

The question of whether to inform patients that they are dying also may come up with patients who are not from a different culture, and, when this happens, may make decision making even more difficult and complex. Even in the U.S. and other countries that prioritize the autonomy of patients, there are some families who do not want clinicians to tell their loved ones that they are dying; family members want to receive this information, not have it given to their loved ones. Ethically, not telling patients that they are dying, because this is what their family members want, may respect the autonomy of these patients. Legally, in the U.S., patients have the right to receive information, but also have

the right to decline information. This applies to all patients. To best respect the preferences of these families and patients, we can ask, before there is a diagnosis, who should receive important medical information from us. It may be that we should ask patients first, since it may make it easier for patients to say, initially at least, that they don't want to receive medical information.

Applying an algorithm. Policies that are based on an algorithm may have implicit, psychological clout, because they are empirically based. Thus, they may have the same effect and exert the same pressure as a consensus-based directive. Given this, it may be optimal to question what a policy that is based on an algorithm says we may or must do before we reflexively follow it. One example of such an algorithm has already been adopted in clinical practice: it can be used to more specifically determine when a patient is likely to die. When patients enter a hospital, this algorithm is applied. Clinicians who practice in hospitals that compute this information can give patients that information, and when patients don't want the information, it is placed in their electronic medical record.[19]

There are strong rationales for the use of such an algorithm. For example, when patients know more about their prognosis, they are better able to make choices about their treatment. But there may be a subtle, less positive effect for patients, whether they choose to be informed or not: clinicians have more information about when their patients are likely to die, and so may be more likely to emotionally "distance" themselves from patients who may die soon. This may occur outside clinicians' knowledge and control, a response that may be unconsciously driven by anticipatory grief.

When we emotionally distance ourselves from patients, patients' emotionally intimate responses to us may diminish in response. What can we do, knowing this, but having no capacity to influence hospital policy? We could conceivably tell patients before they come into the hospital that the hospital has this policy. We could then perhaps explore with patients whether they would want to go to a different hospital. This would create fewer problems for patients for those of us who have admitting privileges at another hospital.

Consensus May Reflect Bias

Consensus may unjustifiably favor one point of view over another point of view. Experts may share a biased view but not realize that they do. The above examples regarding a PEG for patients with dementia and children with profound special needs can be examples of this. When experts share a bias, the consensus document they write will reflect this bias. A possible example is that of disorders of consciousness (DoCs), also called impaired consciousness, when a person's consciousness is affected by damage to the brain. The stage of DoC that I will focus on here is what we used to call a persistent vegetative state (PVS). It was thought that patients in a PVS couldn't—and never would be able—to feel and think, because the outer brain parts necessary for this didn't function, and wouldn't function in the future. It was thought that these patients only had lower brain parts functioning sufficiently to keep them alive. We now know better: these patients may already be aware and, even if they aren't, it is possible that they may become so.[20] Thus we have changed the name of the state that describes the period before patients have awareness, or before we know of it, from PVS to chronic vegetative state (CVS).[21]

A new question that this raises is what clinicians should tell families when patients come into an emergency department with a DoC, in an unresponsive state.[22] We can tell family members the whole truth, or all truths as we know them. For example, we can say that the patient may do well, but, if this happens, it is likely to be in the next four weeks. If the patient doesn't do well in the next four weeks, the patient's prognosis will become increasingly bleak.

But the American Academy of Neurology (AAN) advises doing otherwise.[23] Its consensus advice is based on a fear that if family members are given this information at the earliest possible time, they may prematurely choose—if they can—to withhold or withdraw care, because they fear the bleakest possible outcome for their loved one. Thus AAN advises waiting 28 days, four weeks, to tell family members about their loved one's future prognosis.

The question is clear: Is this recommendation the soundest possible? Or does it too much reflect the bias of the members of the AAN? While we consider this question, we should also consider the opposite option. That is, if patients' family members are told from the outset that their patient may have awareness or come to gain awareness over time, and that their family may make a choice about continuing treatment, families may not then—or ever—be able to stop life-

prolonging treatment, even when the patient has said previously that the patient would want this. It may seem to family members that withholding or withdrawing treatment would end the life of the patient when the patient may be aware or become aware, and might be able to communicate with family members. This is now more than just conjecture. For family members who know about the latest findings—that patients may have awareness or may acquire it and survive—deciding what to do can be excruciating. For example, when family members are told that their loved one may have, or may gain, awareness, they may not feel able to withdraw or withhold life-preserving care. For family members who know that their loved one generally opposed prolonged treatment, knowing the latest data may not be enough to help them avoid these horrible choices.

I have found that the angst that family members feel can be relieved somewhat when I help them sharpen the questions that they ask themselves. I say, "Suppose [your loved one] was able to know all of the latest data. Suppose [your loved one] knew it was possible to have or regain awareness, and even recover. Would [your loved one] want to be kept alive in this state?" These sharpened questions have moved some family members to feel certainty when previously they could not. One family member told me, "Yes, I'm sure [my loved one] wouldn't want that." This family member and others in the family then were able to feel, for the first time, that they were making the right choice. They were doing for their loved one just what they believed their loved one would have wanted.

SPECIFIC CASES

Pressure to comply with consensus may be imposed by the law even when its requirements aren't absolute. Widely accepted ethical requirements may also pose this kind of pressure. I will now discuss some of the cases presented in this issue of *JCE* to explore when we should question consensus-based recommendations and whether we should ever depart from them.

A Hospitalized Adolescent Refuses Vaccine

In this issue of *JCE,* Kious, Hesse, and Baese describe the case of Patient S, 17 years old, "with histories of major depressive disorder, polysubstance dependence, and an episode of psychosis due to intoxication."[24] Patient S gained about 45 pounds while taking antipsychotics, and then, in a residential program, she refused solid food and lived on nutrition shakes and lost more than 65 pounds. She was admitted to the hospital for nasogastric feeding and then transferred to inpatient psychiatry. There, with her parents' consent, she was forcibly medicated when she refused all interventions and oral therapy. This is legal in Utah, where she and her family lived. Over time she improved with the institution of a behavioral program. Her parents believed she would do better at a residential program, but the program required vaccination for COVID-19. Patient S refused to be vaccinated. Her parents insisted. Her clinicians disagreed with one another about forcible vaccination. One staff member withdrew from her case. The ethics consultants who were contacted regarding the case were highly ambivalent.

The case raises many ethical questions. For the purpose of this discussion, there is the particular question of the moral weight that clinicians should give to parents' authority when their view differs from that of the adolescent, and the young person's health is at stake. It may be that our top priority should be to preserve our relationship with the family, in this case, the parents. But there are new developments that address such priorities. One development, for example, urges increasing a child's say in decision making.[25] Another development, more on point in regard to giving priority to maintaining relationships, urges clinicians to meet with parents and children earlier, before conflicts arise, to prevent conflicts, if possible.[26]

In considering this case, we should acknowledge the plethora of new ethical problems that have sprung up with the departure of *Roe v. Wade.*[27] One dilemma is whether we should defer to consensus, in this case one that is imposed by the law. In many U.S. states, if a minor wants an abortion without her parents knowing, she can appeal to a judge to give her this option.[28] But adolescents in these states may not know this. The ethical dilemma for clinicians is whether we should take the initiative to inform a minor who might want to know about her ability to appeal. Transparency and respect for the minor's autonomy would seem to strongly favor this.

In the case of Patient S, described above, the law favors the interests of parents. Laws that offer a minor the possibility to appeal to a judge regarding abortion without parental permission

favor the interests of adolescents. These laws move in opposite ways and pose a question regarding the extent to which we should take consensus-derived laws into account when we make clinical decisions for our patients.

An Older Patient Suddenly Refuses Dialysis

As described in a case by Silva and colleagues published in this issue of *JCE,* a patient who had undergone dialysis for years suddenly wanted to stop.[29] She had a history of depression and said that the guilt she felt was one reason she wanted to stop treatment. It is well known that feelings of guilt may come about suddenly and may be so extreme that they darken and reverse all joyous feelings. Given this, the clinicians in this case faced an additional problem: the patient was examined by psychiatry and was found to be lucid. Often when patients clearly understand treatment options and consequences, it overrides all other considerations and is enough for clinicians to see the patients as having decision-making capacity, and for the law to judge them as competent. This may be seen as respecting patients' autonomy when there are arguments for and against attributing capacity. This patient's clinicians faced implicit pressure to follow the patient's wishes to stop dialysis. They chose to depart from consensus-derived considerations and prioritized what they believed was best for her.

HENRY MARSH

Henry Marsh is one of Britain's foremost neurosurgeons. In his memoir, *Do No Harm: Stories of Life, Death, and Brain Surgery,* Marsh describes a patient who was a school teacher in his late fifties.[30] This patient had a massive brain tumor at the base of his skull that would eventually destroy his hearing, rob him of the ability to walk, and eventually kill him. Marsh believed that he probably could remove all of the tumor. Marsh knew, too, that the surgery could cause terrible consequences. It did. After the surgery, the patient spent 35 years lying in a fetal position, unresponsive, in a nursing home bed. Marsh reports that he knew when he made the choice to try to remove all of the tumor that his colleagues could go two different ways about this aggressive approach. Those who were less experienced wouldn't "try" to remove all of the tumor, but be satisfied with removing most of it. They might believe they had too little experience to be so bold, because they were early in their careers. Marsh knew that more experienced neurosurgeons who had performed this surgery had accomplished results that were, in his words, no less than "amazing."[31] Given this, what should he do? He knew that he was less experienced. Still, in the midst of the surgery, he chose to proceed aggressively.

Perhaps Marsh could have asked the patient before surgery what he would want should this question arise, although alerting him before the surgery could have frightened him. In any case, Marsh's dilemma mirrors the conflicts faced by clinicians when they try to decide whether to deviate from consensus, as discussed throughout this article. Consensus-based directives, whatever their source, warrant respect. Yet there often is a conflict between consensus and our duty to use our own best judgement, tailored to each individual patient we see. We may fear that a decision to depart from a guideline may reflect our unidentified hubris, as opposed to our insight. The emotions we feel when we decide, on our own, what to do may cost us dearly, for many reasons.

Marsh describes his subsequent feelings. Neurosurgeons, he says, often cannot avoid leaving "a trail of injured patients" behind. He adds that one has to be "a bit of a psychopath" to carry on, or at least "have a pretty thick skin."[32] Before performing that surgery, Marsh enjoyed playing his favorite music, by Abba and Bach, as he operated. He reports that he has not played music when he operates, ever since.

CONCLUSION

Directives typically reflect some kind of consensus. We can use them as a guide to what we should do, or as a starting point to better determine our "burden" in deciding whether to follow a directive or go a different way on our own. I have offered many examples to consider this, in which have included patients with dementia who need a PEG, withholding information from patients at their family's request, departing (or not) from policies, and what to tell loved ones when a patient has a DoC and has continued to remain in a CVS. Specific cases have provided additional examples of conflicts in this same area. These cases included an older teenager who refused a COVID-19 vaccination, adolescents who seek permission to have an abortion without their parents knowing, and whether to

override a lucid patient's refusal to continue dialysis.

I ended this discussion by citing the experiences of a neurosurgeon who struggled with a decision not unlike those posed in the cases described above. He chose to proceed with surgery that was unsuccessful, and he hurt. I cited this case to illustrate that when clinicians must choose between following a formal or informal consensus and choose not to follow consensus, they may face inordinate pain. When we face challenging decision points to do what is best for our patients, we will need courage.

Finally, I offer that if clinicians are hurt, as Marsh was, after they choose to go another way, they shouldn't feel guilt or shame when they realize that they did not sufficiently prepare themselves for the consequences of their actions. They may become more resilient as a result. This is a new topic that goes beyond what I have addressed here. This point is still essential. If clinicians seek to decide whether to depart from a directive and feel pain as a result, as Marsh did, they should not feel that they have failed in any way because they have remained vulnerable to being hurt. Rather, they should feel relieved. This means that they care. As Marsh says, we aren't psychopaths. This, then, is a final consensus-based directive.

NOTES

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1. A.L. Brummet and J.C. Watson, "An Argument for Standardized Ethical Directives for Secular Healthcare Services," in this issue of *The Journal of Clinical Ethics* 33, no. 3 (Fall 2022).

2. J.D. Moreno, *Deciding Together: Bioethics and Moral Consensus* (New York, N.Y.: Oxford University Press, 1995).

3. B.M. Kious, T. Hesse, and P.L. Baese, "Involuntary COVID-19 Vaccination of a Mature Minor during Inpatient Psychiatric Treatment," in this issue of *The Journal of Clinical Ethics* 33, no. 3 (Fall 2022).

4. O. Silva, D. Jaber, A. Chiu, C. Adams-Mardi, and E. Wicht, "Depression and Capacity to Withdraw from Dialysis," in this issue of *The Journal of Clinical Ethics* 33, no. 3 (Fall 2022).

5. See, in general, J.W. Worden, *Grief Counseling and Grief Therapy,* 5th ed. (New York, N.Y.: Springer, 2018). For examples of how grief counseling can be offered in directives, see R.A. Neimeyer, *Lessons of Loss* (Memphis, Tenn.: Center of the Study of Loss and Transition, 2006), 58-9, 63.

6. Patients may experience deep and genuine regret. In those cases, clinicians may need to respond in a wholly different way. We must help patients to see that, as humans, we cannot *not* err. The hardest task is when a patient has made a bad choice that the patient *intended* to make. In those cases, a way to respond is to suggest that what the patient has done in the past is not who the patient is now, and, regardless of the past, the patient still has the present and a future. Even if the patient is a serial murderer.

7. E.L. Sampson, B. Candy, and L. Jones, "Enteral Tube Feeding for Older People with Advanced Dementia," *Cochrane Database of Systematic Reviews* 2009, no. 2 (15 April 2009): CD007209.

8. N. Davies et al., "Enteral Tube Feeding for People with Severe Dementia," *Cochrane Database of Systematic Reviews* 8, no. 8 (13 August 2021): CD013503.

9. I.H. Hochwald et al., "Ethical Challenges in End-stage Dementia: Perspectives of Professionals and Family Care-givers," *Nursing Ethics* 28, no. 7-8 (November-December 2021): 1228-43.

10. I. Halevi Hochwald et al., "Emotion Work and Feeling Rules: Coping Strategies of Family Caregivers of People with End Stage Dementia in Israel: A Qualitative Study," *Dementia* 21, no. 4 (May 2022): 1154-72. One caregiver said, "It is not hard, it's fun."

11. Y.F. Lee et al., "The Efficacy and Safety of Tube Feeding in Advanced Dementia Patients: A Systemic Review and Meta-Analysis Study," *Journal of the American Medical Directors Association* 22, no. 2 (February 2021): 357-63.

12. P. Silván-Ferrero, P. Recio, F. Molero, and E. Nouvilas-Pallejà, "Psychological Quality of Life in People with Physical Disability: The Effect of Internalized Stigma, Collective Action and Resilience," *International Journal of Environmental Research and Public Health* 17, no. 5 (10 March 2020): 1802. For an example of what parents can pursue, see P. Rytterström, M. Borgestig, and H. Hemmingsson, "Hope and Technology: Other-Oriented Hope Related to Eye Gaze Technology for Children with Severe Disabilities," *International Journal of Environmental Research and Public Health* 16, no. 10 (14 May 2019): 1667.

13. G.L. Albrecht and P.J. Devlieger, "The Disability Paradox: High Quality of Life Against All Odds," *Social Science & Medicine* 48, no. 8 (April 1999): 977-88. These authors state that it is "fundamental" to address disability in terms of salutogenesis—that is, as a positive adaptation and resolution to stress, as opposed to pathogenesis, or considering a disability as pathological.

14. K.R. Hexem, A.M. Bosk, and C. Feudtner, "The Dynamic System of Parental Work of Care for Children with Special Health Care Needs: A Conceptual Model to Guide Quality Improvement Efforts," *BMC Pediatrics* 11, no. 95 (25 October 2011): 95. I offer as an example a child who could neither talk or walk, and never would. She could, though, bang her doll on the floor when there was something that she wanted. Her older siblings, from her birth, enjoyed playing with her immensely, and her shrieks of joy

suggested that the enjoyment was mutual. She was the delight of her family.

15. L.M. Crawley, P.A. Marshall, B. Lo, B.A. Koenig, and the End-of-Life Care Consensus Panel, "Strategies for Culturally Effective End-of-Life Care," *Annals of Internal Medicine* 136, no. 9 (7 May 2002): 673-9; M. Kagawa-Singer and L.J. Blackhal, "Negotiating Cross-Cultural Issues at the End of Life: 'You Got to Go Where He Lives,' " *Journal of the American Medical Association* 286, no. 23 (19 December 2001): 2993-3001; M.D. Feldman, J. Zhang, and S.R. Cummings, "Chinese and U.S. Internists Adhere to Different Ethical Standards," *Journal of General Internal Medicine* 14, no. 8 (August 1999): 469-73.

16. A.J. Davis, E. Konish, and T. Mitoh, "The Telling and Knowing of Dying: Philosophical Bases for Hospice Care in Japan," *International Nursing Review* 49, no. 4 (December 2002): 226-33; S. Matsumura et al., "Acculturation of Attitudes toward End-of-Life Care: A Cross-Cultural Survey of Japanese Americans and Japanese," *Journal of General Internal Medicine* 17, no. 7 (July 2002): 531-9; B.B. Gabbay et al., "Negotiating End-of-Life Decision Making: A Comparison of Japanese and U.S. Residents' Approaches," *Academic Medicine* 80, no. 7 (July 2005): 617-21.

17. C. Gómez-Vírseda, Y. de Maeseneer, and C. Gastmans, "Relational Autonomy in End-of-Life Care Ethics: A Contextualized Approach to Real-life Complexities," *BMC Medical Ethics* 21, no. 1 (30 June 2020): 50.

18. For this reason I highly value regular interaction with patients who are chronically ill, even when I have little to offer. Counterintuitively, perhaps, shared humor may be the best one has to offer, and it may give patients at least this to look forward to.

19. P.Y. Brossard, E. Minvielle, and C. Sicotte, "The Path from Big Data Analytics Capabilities to Value in Hospitals: A Scoping Review," *BMC Health Services Research* 22, no. 1 (January 2022): 134; W. Ben Ali et al., "Implementing Machine Learning in Interventional Cardiology: The Benefits Are Worth the Trouble," *Frontiers in Cardiovascular Medicine* 8 (8 December 2021): 711401.

20. A.L. Goss and C.J. Creutzfeldt, "Prognostication, Ethical Issues, and Palliative Care in Disorders of Consciousness," *Neurologic Clinics* 40, no. 1 (February 2022): 59-75.

21. This gain of awareness within VS patients may be as many as 20%. Ibid.

22. There has been recent debate around whether clinicians are obligated to disclose to families of patients with VS that some patients with VS may demonstrate covert awareness by investigational neuroimaging. From the first moment in an emergency department or intensive care unit, family members must simultaneously learn new medical information, navigate new systems of care, and confront financial barriers, all the while possibly being in shock and grieving. Savulescu and Kahane assert that patients' isolation may be far worse than someone in solitary confinement, and thus, ending their lives may be not only permissible, but morally obligatory. J. Savulescu and G. Kahane, "Brain Damage and the Moral Significance of Consciousness," *Journal of Medicine and Philosophy* 34, no. 1 (February 2009): 6-26. The quality of life of these patients, though, on the other hand, may depend at least somewhat on their social support, as has been considered above regarding patients with dementia and severely impaired children.

23. The AAN now recommends that when clinicians discuss with loved ones the prognoses of patients with acute DoCs, they do not note during the first 28 days after injury that the patients may later, universally, have poor prognoses. Goss and Creutzfeldt, "Prognostication," see note 20 above. See also J.T. Giacino et al., "Practice Guideline Update Recommendations Summary: Disorders of Consciousness," *Archives of Physical Medicine and Rehabilitation* 99, no. 9 (2018): 1699-709; and W.S. van Erp et al., "Unresponsive Wakefulness Syndrome: Outcomes from a Vicious Circle," *Annals of Neurology* 87, no. 1 (2020): 12-8.

24. Kious, Hesse, and Baese, "Involuntary COVID-19 Vaccination," see note 3 above.

25. I. Coyne, I. Hallström, and M. Söderbäck, "Reframing the Focus from a Family-Centred to a Child-Centred Care Approach for Children's Healthcare," *Journal of Child Health Care* 20, no. 4 (December 2016): 494-502.

26. Y. Hasegawa and H. Gleeson, "Three Practical Principles in Planning and Developing Health Care Transition: Our Personal Perspectives," *Clinical Pediatric Endocrinology* 27, no. 3 (2018): 109-12; S. Knutsson, M. Golsäter, and K. Enskär, "The Meaning of Being a Visiting Child of a Seriously Ill Parent Receiving Care at the ICU," *International Journal of Qualitative Studies on Health and Well-Being* 16, no. 1 (December 2021):1999884; M. Prior, M. McManus, P. White, and L. Davidson, "Measuring the 'Triple Aim' in Transition Care: A Systematic Review," *Pediatrics* 134, no. 6 (December 2014): e1648-61.

27. *Roe v. Wade,* 410 U.S. 113, 22 January 1973.

28. As of 1 August 2022, 35 U.S. states include a judicial bypass. Guttmacher Institute, "Parental Involvement in Minors' Abortions," *https://www.guttmacher.org/state-policy/explore/parental-involvement-minors-abortions.* See also American College of Pediatricians, "Parental Notification/Consent for Treatment of the Adolescent," *Issues in Law and Medicine* 30, no. 1 (Spring 2015): 99-105, 99.

29. O. Silva et al., "Depression and Capacity," in this issue of *JCE.* See also C.R. Butler et al., "Ethical Concerns in the Care of Patients with Advanced Kidney Disease: A National Retrospective Study, 2000-2011," *Journal of General Internal Medicine* 35, no. 4 (April 2020): 1035-43.

30. H. Marsh, "Hubris," *Do No Harm: Stories of Life, Death, and Brain Surgery* (New York, N.Y.: St. Martin's Press, 2014): 207-14.

31. Ibid., 209.

32. Ibid., 210.