

12-2021

Including a Chaplain and Culturally Sensitive Notary in End-of-Life and Earlier Difficult Healthcare Issues

John Stonestreet

HopeCare, drjohnstonestreet@gmail.com

Follow this and additional works at: <https://aquila.usm.edu/ojhe>



Part of the [Bioethics and Medical Ethics Commons](#), [Health Communication Commons](#), and the [International and Intercultural Communication Commons](#)

Recommended Citation

Stonestreet, J. (2021). Including a Chaplain and Culturally Sensitive Notary in End-of-Life and Earlier Difficult Healthcare Issues. *Journal of Health Ethics*, 17(1). <http://dx.doi.org/10.18785/jhe.1701.07>

This Article is brought to you for free and open access by The Aquila Digital Community. It has been accepted for inclusion in *Journal of Health Ethics* by an authorized editor of The Aquila Digital Community. For more information, please contact Joshua.Cromwell@usm.edu.

Including a Chaplain and Culturally Sensitive Notary in End-of-Life and Earlier Difficult Healthcare Issues

Cover Page Footnote

Author Copyright 2021. All rights reserved, including ideation.

Including a Chaplain and Culturally Sensitive Notary in End-of-Life and Earlier Difficult Healthcare Issues

John Stonestreet
HopeCare

In a video segment from the PBS Frontline documentary that accompanied Dr. Atul Gawande's best-selling book, *Being Mortal*, Gawande (2015) makes a startling admission. The admission takes place in the context of a conversation Gawande is having at the kitchen table of Rich Monopoli, the husband of Sara Monopoli, a Gawande patient who died of cancer at the age of 34. Several years had gone by since Sara's death, and her husband Rich was kind enough to invite Gawande into his home to rehash the conversations surrounding treatment decisions that they previously had as doctor-patient/family. Gawande prefaces the exchange with Rich by stating that Sara's cancer was not curable, and that he really should have leveled with the family and, ultimately, tried to help them prepare for how they wanted to experience their final months together before Sara's impending death. But he confesses that he simply could not bring himself to tell this young family the truth. Sara had recently given birth to a dear baby girl, and Gawande could not bring himself to shed such devastating light on the reality this bright young family was unknowingly facing. Speaking with Sara's husband Rich, who tearfully recounts the "excruciating" experience his family went through from so many ill-advised and unhelpful treatments, Dr. Gawande reveals that his willful dishonesty unfortunately contributed to this family's suffering. In short, Gawande broke the cardinal rule of medicine—"do no harm"—and was admittedly guilty of blatant maleficence. Here is how he narrates what happened:

When I came on the scene was when she got diagnosed with a second cancer [thyroid cancer in addition to the previous lung cancer]. In my mind what I was thinking was I wouldn't offer this surgery because the lung cancer was going to take her life. And yet I didn't feel I could say that to you. I think we started talking about the experimental therapy that you all were hoping to get on for a trial for the lung cancer, and I remember saying something I sort of regret, which was, "you know, maybe that experimental therapy will work for the thyroid cancer too." [laughing] I said that. I know it was complete...I knew it wasn't gonna... in other words, the reason I regret it is because I knew it was a *complete lie*. I just was wanting something positive to say (Ibid, italics mine).

Not surprisingly, Rich responds: "I did not know it was an outright lie." Patients and families naturally expect to get the truth from all physicians, not to mention New York Times best-selling world-famous physicians from Harvard. Staring Gawande directly in the eyes, Rich continues: "You could lose your license for that." Gawande cracks up laughing and says, "I know!"

But is that so? Could Gawande really lose his license for this act of medical maleficence? Obviously not, or else he probably wouldn't be admitting it on national television. Short of losing his license, is there any penalty at all for communicative maleficence? Short of penalty, are there even any formal or informal measures in place to prevent or reduce this kind of tragically harmful communication by well-meaning physicians?

Amazingly not. Neither this particular incident nor the larger observation is meant to reflect poorly on Dr. Atul Gawande. As everyone already knows, Gawande is among medicine's very best and brightest. His self-awareness, transparency, and courage are the keys that open this secret vault of communicative maleficence and allow us to reflect on its tragic implications and discern whether or not we intend to do anything about it.

What was the context and outcome of Gawande's communication failure?

Reflecting back, Gawande confesses to Rich, "I don't think I was terribly equipped for having that conversation...and maybe you all weren't." Rich responds, "I don't think we were." If neither doctor, nor

patient, nor family was equipped for a conversation that everyone agrees in hindsight should have occurred, then how are such conversations to occur under such trying circumstances? Could it be that Dr. Gawande, patient Sara, and husband Rich needed a third party in the room who was a little more equipped for ensuring that Gawande didn't get away with telling a "complete lie" that he now regrets?

Such communication accountability would not necessarily require a rocket scientist. Perhaps all that was needed in hindsight was a little bit of structural accountability surrounding shared understanding. How might third-party structural accountability have changed the conversation Gawande had with the Monopoli family?

What if, after Gawande told that "complete lie" about experimental chemo potentially curing a comorbidity it was never even meant to address, a third party to the conversation simply asked two simple questions? "Rich and Sara, would you like to repeat back to Dr. Gawande what you just heard him say?" Then, when they repeated the lie back to Gawande in front of said third party serving as a witness to veracity, only one more question would be necessary: "Dr. Gawande, is that what you wanted Rich and Sara to hear, and is there anything else you want to add to help them understand what you are seeing and thinking?"

With such a simple, innocent prompting, it seems very unlikely to me that Gawande would have told the same lie twice, especially if he knew the conversation was being recorded subject to later ethical oversight. In hindsight, Gawande confessed that the reason he lied is because he was "just wanting something positive to say." This is a confession of understandable discomfort addressing the elephant in the room. Perhaps all Gawande needed was another swipe at delivering what physician communication trainers at VitalTalk might call an effective "headline" for the reality that the Monopoli family may be facing (Back, Arnold, & Tulskey, 2021).

If a third party were present to ask those two simple questions, might Gawande have swallowed hard and managed to eke out a more truthful headline on his second attempt? Under the right conditions of inescapable accountability, where Gawande felt the same kind of responsibility that medical researchers feel under the watchful ethical eyes of Institutional Review Boards (IRBs), I would think yes. All he needed, in my view, was a pitcher on the mound (i.e. - third-party communication facilitator in the room) to give him one more swing at it. Given the opportunity to swing at a second conversational pitch, my money would be on Gawande to follow his first strike with a base hit if not a home run.

If that is the case, then should there be a third party inserted into these conversations whose job it is to provide some accountability around shared understanding on information that doctors struggle to deliver and patients and families struggle to hear? That was indeed the closing suggestion of one profoundly penetrating ethnographic study. The, et al., (2001) observed a "Collusion in Doctor-Patient Communication About Imminent Death" (p. 247). Their conversation analysis traced a systematic pattern of conversational movement away from prognosis understanding and toward the logistical details of planning the next, tacitly presumed, treatments. This pattern prevails whether or not the treatments are likely to make the dying patient's suffering more bearable.

As Rich put it in reference to Sara's treatment decisions in response to Gawande's lie, they "made her sicker, and sicker, and sicker" (Gawande, 2015). Rich goes on to recount that "the chemo made her so weak that she couldn't even hold [her daughter] Vivian. It was exhausting. And that was not a good outcome in the final months. It's not where we wanted to be" (Ibid).

The "doctor-patient collusion" toward avoiding difficult prognosis conversations in favor of discussing the mindless mechanics of often futile and even harmful treatments is nothing short of a global pandemic. Palliative care and hospice exist to alleviate this systemic suffering. But despite best efforts, truly favorable outcomes are still limited. While the palliative/hospice movement celebrated increased hospice enrollments in the first decade of this century, palliative physician researcher, Randy Curtis, popped that bubble for me in a palliative care workshop I attended at Harvard Medical School in 2013. Citing the latest research, Curtis pointed out that too many hospice enrollments were occurring too

late in the dying trajectory, skewing the statistics on the effectiveness of the movement in demedicalizing death and alleviating unnecessary suffering. According to Curtis, last minute transfers from hospice, while they might read well to a shortsighted statistician, may actually be as likely to cause suffering as to alleviate it. After all, who wants to endure the discomfort of physical relocation in the final moments, hours, or days of life? Dying in a hospice bed rather than an intensive care unit (ICU) bed might look great on a hospice utilization stat sheet, but is it really moving the needle on the elimination of suffering if it happens so late in the game? Would Rich reflect differently on Sara's final weeks and months if she had been shuttled to a hospice bed the day before she died? Perhaps. And perhaps not.

I witnessed this reality first hand as a spiritual care provider in hospice. For the patients who were fortunate enough to spend their final months in hospice, the regimen focused on reducing physical suffering through pain relief and maximizing spiritual and emotional healing through initiatives like legacy building, spiritual care, and music therapy, were profound. But far too many patients failed to benefit from the multifaceted approach to healing that hospice provides. This is no fault of the hospices which do their best with what they are given. Rather, the real culprit is an upstream systemic failure in communication surrounding end-of-life healthcare decision making.

At the risk of picking a bone with the dogmatic defenders of modernity's most pervasive and unacknowledged myth (and with a respectful nod to Jeffrey Bishop¹), I will call this systemic communication failure an unconscious subservience to a *scientistic* imperative. By *scientistic* imperative, I am referring to a focus on the purview of science, what and how of treatment, rather than the larger questions that hover outside of the scientific lens of modernity's microscope. Medical science has succeeded in granting powerful human knowledge by virtue of airtight systems of manipulation and control. As such, medical science presents a very powerful and efficient hammer. And patients present a nail. This is what ethnographers functionally trace in their study of physician-patient/family communication at the end of life: a big hammer desperately seeking out smaller and smaller nails to pound, pound, pound until the coffin is suddenly nailed shut before anyone even got the chance to say goodbye (The et al., 2001). Put another way, this reality may be best represented by a popular joke that might be funny if it weren't so sad: "Why do they put nails in coffins? To keep oncologists from getting in there to deliver another round of chemo."²

Reflecting together with Dr. Gawande, in hindsight, on how this dynamic played out in the life of the Monopoli family leading up to the death of his young wife, Sara, Rich Monopoli says: "I've thought often about, what did that cost us? What did we miss out on? What did we forgo by consistently pursuing treatment after treatment after treatment?" As Rich recounts with glistening eyes and trembling lips, "we should have started earlier with the effort to have quality time together."

The story told by Rich's trembling and tears, even years after the event, is a story of tragic medical maleficence. Dr. Gawande's lie caused harm to the Monopoli family. Perhaps Gawande knows this full well, and that is why he is man enough to admit his regrets and raise awareness for systemic change. The sad fact might be that a world without Dr. Atul Gawande might be something like a world without Darnella Frazier, the young woman who recorded with her cell phone the final moments of George Floyd's life. Like law enforcement officials, physicians exercise tremendous authority and influence in our lives, and, for the most part, that authority and influence goes unexamined. Unfortunately, lack of accountability in interactions with such marked power differentials often results in secret suffering and silent harm. In the case of the Monopoli family, Gawande's desire to have "something positive to say" was forgetful that historically, the four principles of bioethics were not

¹ Physician philosopher of medicine Jeffrey Bishop (2011), unveiled the *scientistic* lenses through which medicine has its way with patients and their families, even, and especially, in the course of dying. Bishop sees this "metaphysics of efficient causation" operative in both ICU and palliative care culture.

² I include this joke with some remorse, because it is not fair to a great number of complexities, including the love, care, and pain felt by oncologists, who are doing everything they can to help suffering patients.

always on equal footing. There was a clear priority for the principle of greatest preference: “*First*, do no harm.” Sadly skipping rule number one, non-maleficence, Gawande’s attempt at beneficence turned out to be a tragically counterproductive breach of medical ethics.

If someone as capable as Atul Gawande is guilty of such regrettable harm, could it be that we are assuming and tacitly expecting too much of physicians when it comes to high stakes, high touch communication? If healthcare is going to start taking communication more seriously, then the dream team for the future of shared decision making is currently missing two key players: a chaplain and a notary.

I recently completed the Vitaltalk Faculty Development in DC and Aspen, where I learned skills for training physicians and their teams on effective communication with patients and families for end-of-life (EOL) decision making. Nowhere is the gold standard of shared decision making (SDM) more important than at or near the latter stages of life. The physician leading my small group in the Faculty Development program pulled me aside and told me I would have a special role to play in EOL SDM as a chaplain because chaplains attend to emotions, emotions lead to story, story leads to meaning, meaning leads to values, and values lead to decisions. As a longtime advocate of person-centered care, this all rang true to me and made me wonder: Are physicians making full use of their chaplains, especially for the crucial task of SDM when EOL may be approaching?

Research shows that chaplains connect with patients and families in a way that unearths key issues at stake in impending decisions. One study described a case where the medical team was having trouble connecting with the 26-year-old daughter of a dying 56-year-old woman for a shared decision on potential withdrawal of life support (Hughes et al., 2007). The chaplain connected with the daughter’s emotions of grief and fear and was able to unearth the story that made sense out of the situation. The 26-year-old daughter had been in a similar situation 4 years previously with her then one-year-old son. Bearing the weight of letting go of her son as a single mother, she finally decided to withdraw life support. But the story didn’t end there. Her son rallied unexpectedly and lived on as a special needs child with a high degree of dependence. Re-living that same decision of removing life support for her mother took her back to the grief over what happened to her son and also took her forward into imagining what it would be like if her mother also rallied enough to live on. Would her mother require total care too? How would she be able to care for her mother while continuing to care for her highly special needs child and her other two children? Her fear imagining that scenario was complicated by a tremendous amount of grief from reliving what she previously went through with her son. In this case, the patient ended up dying shortly after the chaplain conversed with the daughter, so a decision for withdrawal of life support was never made.

In hindsight, the chaplain believes the medical team would have saved a lot of time and energy trying to get the daughter to make a decision if they had engaged the chaplain sooner to follow the emotions and unearth the story. But physicians are not always keen to engage chaplains earlier on, and some are even resistant when chaplains seek to engage them. Chaplains observe that “many physicians do not speak realistically about prognosis or the expected outcome of medical interventions nor do they make room for goals of care conversations” (Wirpsa et al., 2019, p. 36). But it isn’t always productive for a chaplain to bring these issues to a physician’s attention. As one physician said:

Sometimes, the chaplain will come and they’ll tell the physician or whoever is in charge, “Look your patient is asking for this, this and that.” And sometimes unfortunately the response is, “Don’t tell me how to take care of my patients. I’m the one who went to medical school. You can tell them if they need to go to church.” Unfortunately, there’s not the [pause] [teamwork]. There’s the perception sometimes although we’re all a team, the physician, rightfully ... that they’re the team leader. And it’s true they are the team leader. At least in our set up here, they are the team leader. But a good team leader has to take input [chuckles] from everyone. But

sometimes, it's like you know if you had all the time in the day to take care of one patient, you would listen. But when if you've got other things to do (Nedjat-Haiem et al., 2017, p. 315).

So, some physicians think chaplains need to stay in their own lane, and even if the chaplain has a valid point, physicians are always saddled with overwhelming limitations on their time. This raises the questions, what is the chaplain's lane? Are there points where the chaplain's lane merges into the physician's lane? And is there some way that physicians and chaplains can work together on SDM that would enable physicians to save precious time rather than lose it?

There do seem to be points where the physician's lane and the chaplain's lane merge. On some occasions, this even happens on the physical plane of the patient's condition. One study found that "spiritual disease management can sometimes shed insight about a patient's physical disease status" (Kuziemyk et al., 2009). The chaplain in this case was able to uncover diagnostic data that had eluded the physician. Although the patient was in extreme pain, this was not known to the physician. The patient felt close enough to the chaplain to disclose both the presence of intense physical pain and the reason for keeping it from the physician: the patient had a fear of opioids. So physical information was buried in an emotional hole. The chaplain, then, does sometimes merge into the physician's lane, and the physician likewise, often merges, or often has opportunities to merge, into the chaplain's lane through SDM (for an example of such opportunities, see Stonestreet, 2019).

A hallmark of SDM is solicitation of patient values to inform considered decisions. If my Vitaltalk physician mentor was correct that the values leading to decisions are embedded in the meaning patients make of their illness, and their meaning making stems from their story, and their story is unlocked through their emotions, then this process brings two things to mind: a chaplain's job description and a time-intensive endeavor.

Indeed, time is the biggest barrier to SDM implementation (Boland et al., 2019). Pieterse et al. (2019) called for system/policy changes to allow more time for SDM, imploring that we "invest in innovations that create time" for physicians to do justice to the ideal of SDM (p. 26). Fried (2019) suggested an important innovation in SDM, but this innovation, while right on the mark, may only exacerbate the time conundrum. Rather than beginning with a shared understanding of values, Fried insists that SDM begin with a shared understanding of the decision to be made. Instead of focusing initially on the details of a recommended treatment or even on the values considerations unearthed through learning more about the patient's previous life outside of the hospital, the idea is to focus first on painting a picture of the most likely outcomes of various treatment alternatives, as this is what really matters to patients and families.

First, it must be said that it is, to put it mildly, a curious situation that as recently as 2019 the *Journal of the American Medical Association's* latest brightest invited opinion piece on SDM was recommending something so commonsensical that it is uncanny that it has not been the standard of care for decades if not centuries. Why is it a novel idea for physicians to begin SDM by describing the likely outcomes of various alternatives? More on that below.

For now, let's focus on Fried's (2019) recommendation and imagine together a physician approaching a family in the ICU, time-strapped, tasked with describing the likely outcomes of various alternatives under consideration for a decision, realizing the importance of eliciting patient values, knowing that can open a big can of worms, and wondering how long the conversation will take. What if the physician brought the chaplain along for this outcome-focused framing of alternatives, briefly acknowledged any family emotions that surfaced in the course of the conversation, and used that acknowledgement as a dovetail to an exit, stating that the chaplain would be able to stay longer? (To further unpack their emotions, understand their story, explore their meaning, discuss their values, and take time to fully consider the decision) The physician could return later for any clarifying technical questions after the family had time to absorb the information, and take ample time with the chaplain to do the emotional work necessary to arrive at a fully considered decision.

Is this a task chaplains are up to doing? Absolutely. Once the physician has medically framed the decision in terms of alternatives and their outcomes, chaplains see themselves as uniquely suited for running with the SDM baton from there.

Chaplains are thoroughly trained to take the time necessary to listen, and hold the emotional space necessary to tenderly invite and fully hear, the patient narrative that grants meaning to the treatment decisions at hand. Chaplains combine the skills of a wilderness tour guide with those of a humble, loving midwife/doula. In other words, chaplains lead by knowing how to follow. What chaplains quietly and tenderly follow is the patient's journey of self-disclosure and exploration of their family history, their life story, and their spiritual values in intersection with their current illness narrative. Witnessing the patient giving birth to the epiphanies unveiled by their uniquely personal story, positions the chaplain to help unearth what really matters to the patient and family as they face a particular healthcare decision. As stated by an esteemed colleague: "Chaplains take a broader view of the lives and identity of patients and families, so we bring a robust narrative competence into the process that invites people to more fully articulate their values and wishes" (Wirpsa et al., 2019, p. 33). And, lest we forget the obvious, "when most people face these decisions, they are thinking about meeting God" (Ibid). Chaplains also believe they are uniquely positioned to advise physicians on optimal timing for broaching sensitive issues related to SDM (Ibid). And we all know that when it comes to broaching difficult conversations, timing can be everything.

Then why don't physicians already incorporate chaplains into SDM conversations with patients and families and leave them for additional processing after the medical options and outcomes are articulated? Some do. And they are the leaders for the future of multidisciplinary EOL SDM across all specialties, not just when there happens to be a chaplain dedicated to the palliative care team. But many do not, perhaps because many physicians still have a limited understanding of what chaplains do (Cadge et al., 2011). Physicians tend to artificially limit a chaplain's scope to be focused on ritual, information, and counseling surrounding death long after critical healthcare decisions have already been made (Ibid). And some physicians who have not yet worked with chaplains incorrectly "worry that chaplains might not listen to patients' concerns," or "might not respect their beliefs" (Ibid, p. 302). But this could not be further from the truth. Research shows that chaplains are very well-received by patients and families of any faith or no faith. National Press Ganey and HCAHPS surveys reveal that patients who were visited by a chaplain were more satisfied with their overall hospital experience, more likely to say that staff met their spiritual needs, and more likely to recommend the hospital (Marin et al. 2015).

Kim et al. (2018) analyzed theories of health care decision making at the end of life and developed a conceptual framework for individual and family end-of-life decision making. The framework reads like a virtual chaplain's playbook. The seven goals of decision making are quality of life, hope, meaning, symptom control, "good death", honor patient, and family harmony. A physician is necessary for symptom control, but the other six goals are more suited to the chaplain's domain. Are chaplains best positioned to answer Pieterse's call for systemic "innovations to create time" for realizing the latent potential of EOL SDM? While we can always dream of systems and policies to remove the physician time crunch threatening the existence, and hampering the effectiveness, of EOL SDM, better utilizing existing communication specialists may just be the most viable option. Chaplains could be the linchpin to EOL SDM effectiveness, a largely untapped resource sitting right under our noses.

In addition to bringing a chaplain into the room for EOL SDM, there may be another party that needs to be in the room, at least via video conference, for all forms of SDM, which means all major healthcare decisions: a specially trained healthcare notary. Why would we need a healthcare notary to certify all major healthcare decisions? Aren't we doing just fine with current practices of informed consent? Unfortunately, not.

The Dartmouth-led Preference Laboratory is an international collaborative, including physicians from Johns Hopkins and other leading institutions, working to improve SDM in healthcare. In their 2017

article on shared decision making, Elwin et al., (2017) emphasize the need for physicians to become competent at SDM because: “We do not believe future generations of patients will tolerate important decisions being made without them understanding the key trade-offs between the harms and benefits of interventions” (Ibid, p. 2). What that statement sadly acknowledges is what we already witnessed in Gawande’s confession above: the current generation of patients is consenting to important medical decisions without understanding the key trade-offs between the harms and benefits of interventions. That is a staggering admission. As disheartening as this may be for the general population, evidence suggests the situation may be even worse for African Americans (Peek et al., 2010a & b). Why is this so? In twenty-first century healthcare, how can this be?

The biggest barrier Elwyn et al identify standing in the way of changing this unfortunate reality is “the attitude of clinicians, who find it difficult to adopt this approach” (Elwin et al., 2017, p. 2). Why do many physicians find it so difficult to bring patients into a fully transparent consideration of the harms and benefits of interventions? In the medical ethics classic, *The Patient as Person: Explorations in Medical Ethics*, Ramsey (1970) speaks of physicians balancing two conflicting imperatives: the “medical imperative” and the “moral imperative” (p. 124). The medical imperative is that doctors relentlessly seek to fight and cure disease. The “moral imperative” is that doctors consider, from a human perspective, what is the best course of action for a particular patient, especially for a patient who may be incurable. For Ramsey, this was a troubling conflict of interest. He repeatedly stated that “the question of questions is whether both judgments (with appropriate actions) can dwell together in the same person and calling” (Ibid, p. 144).

The ethical concerns of Ramsey and others were accounted for by Institutional Review Boards (IRBs) in the field of medical research. But in the realm of non-research treatment decisions, hospital ethics committees never achieved any clear standards for comprehensive accountability for ethical communication surrounding treatment decisions like IRBs achieved for research. So here we are 50 years after Ramsey’s “question of questions” with a Dartmouth-led international collaborative doing its best to advocate for a bright future for SDM with no deadline for fully transparent ethical communication surrounding medical treatment decisions in sight. This tragedy may have a simple fix: require notarized consent to all major healthcare decisions. This could be provisioned for relatively easily using the same video conferencing setup already in use for Remote Video Interpreting (RVI).

But doesn’t a notary just verify an identity and a signature? For an “oath” or an “affirmation,” yes. But not for an “acknowledgement.” For an “acknowledgment,” a notary is required to verify understanding of the document being signed. Recall again the staggering quote above about “decisions being made without [patients and families] *understanding* the key trade-offs between the harms and benefits of interventions” (emphasis mine). In an “affirmation,” a notary verifies *understanding*.

We can’t continue to sheepishly suggest that physicians consider learning and implementing SDM. That would be like merely suggesting after tragedies like Tuskegee that researchers might perhaps consider consulting with IRBs as an elective option (if they have the time and feel so inclined) before conducting research, which we all agree would be preposterous. So why would we continue this insolvent trajectory for SDM? The specially trained, culturally sensitive healthcare notary will do for ethical communication surrounding treatment decisions what the IRB did for research. It will be a formal, concrete provision to ensure ethical communication leading to patient and family understanding for truly informed decisions. Answering the call for communication innovations to help African Americans address the role of racism in SDM (Peek et al., 2010a & b), culturally sensitive healthcare notaries may be the next step forward in pursuit of justice. Why not provide the option for patients and families to select a healthcare notary of their own race, ethnicity, and/or culture? While specialized training can always help, the most profound cultural sensitivity is always easier to embody when it flows instinctively through the veins.

Put another way in the George Floyd era, the culturally-matched, remote-via-video healthcare notary will be live-manning the SDM body cam (or more colloquially the Doctor Body Cam), if you will. The healthcare notary will serve for healthcare a purpose similar to that for which body cams were introduced into law enforcement: accountability increases the chances of achieving the outcomes for which we all hope. In 2012, Dartmouth's groundbreaking study issued a call for accountability in healthcare: "Stop the Silent Misdiagnosis: Patients' Preferences Matter" (Mulley et al., 2012). In 2013, a "protest cry" that would later be called a "new civil rights movement" issued a call for accountability in law enforcement: "#BlackLivesMatter" (Altman, 2015). Earlier that decade, Monica Peek, MD, MPW (2010a & b) laid out evidence that Black Lives are uniquely vulnerable to the "silent misdiagnosis" resulting from the disenfranchisement of patient preferences that SDM thought leaders would decry (Mulley et al., 2012). In law enforcement, a concerted effort was made to ensure accountability via body cams. Will another decade elapse before justice is rendered or even attempted in healthcare?

The Doctor Body Cam is not a new idea. National Institutes of Health (NIH)'s Jeremy Brown made the case for physician body cams in early 2015 (Brown 2015). One of his readers voiced concern around the idea of video capturing footage of naked patients, but that could be prevented by limiting the footage to audio in some, or if necessary, all cases.

It may be argued that police body cams failed to prevent the murder of George Floyd, so why should we bother to pursue similar insolvency in healthcare? Two responses might be made: First, there have always been, and always will be, crimes that law enforcement cannot prevent. Has that ever stopped us from trying, from doing everything possible to increase the chances for justice? Second, while body cams have certainly rendered much justice, the challenges encountered by police body cam implementation can inform the process of pursuing accountability in healthcare.

Healthcare can learn from law enforcement that it is a mistake to rely on power structures to self-enforce. It is not easy for citizens to access body cam footage because that footage is owned and managed by the police force (Matsakis, 2020). This lesson should already be noted by the limited patient/family protections ensured by hospital ethicists and their committees, owned and operated as they are by the hospital systems themselves. There is no escaping the reality that ethicists are structurally aligned with the very forces of power that they are meant to protect patients and families against. Like hospital lawyers and public relations personnel, hospital ethicists serve at the pleasure of the institution and the physicians to whom it caters. Despite the reality of ethical victories for patients and families to the contrary, there is no getting around this structural reality. As a result, many ethicists are not surprisingly more adept at binding patients and families into behavioral contracts than they are at providing accountability for the ethical communication of physicians. The only way for an SDM notary to serve as a truly unco-opted third party is for them to be structurally positioned as unco-opted third parties. How else could a notary possibly fathom any real connection between job security and the rendering of justice? It is not difficult to imagine a scenario where, immediately following a tense patient/family conversation in which she advocated for their voice, a prominent physician could place a call to a hospital administrator, and the notary could suddenly find herself locked into a performance improvement plan. These kinds of things happen every day. If we make an effort to provide accountability for ethical healthcare communication, then we need to endeavor to get it right so we can alleviate and prevent as much suffering as possible.

As a hospital/hospice spiritual care provider, I have borne witness to a significant amount of suffering, and it may be an understatement to say that not all of it was inflicted by physical illness. In the fall of 2012 when Dartmouth took its stand for SDM, I was called to the bedside of Alma, a dear African American woman suffering considerably. As I listened to Alma's story, her chief complaint was emotional suffering from complicated grief as a result of being tragically disenfranchised by the medical team in the days leading up to her husband's recent death (Stonestreet, 2021). The team invited her to arrive at 12:30 PM for a family meeting regarding her husband's potential transfer from ICU to hospice, but the meeting

was already over before Alma arrived at 12:30. As Alma's husband languished unto death in his hospice bed, Alma's grief was complicated by what would become a lifelong, psychologically-destabilizing and physical/mental health-ravaging, torturing-fear that, just as she was unethically disenfranchised from supporting her husband during the hospice transfer conversation, so also her husband may have been unethically disenfranchised by being coerced to sign himself out of the ICU bed and into the hospice bed under duress.

Might a video camera and an African American notary have spared Alma of her complicated grief? Could the black notary have simply asked Alma's husband if there was anyone else he desired to be present for this conversation and decision? If he had replied on camera that he would prefer Alma to be present, could that have prevented the unnecessary complication of her grief? Alternatively, it may not even have come to that. Knowing that the black notary would be present, and the video camera would be running, might the team have thought twice before disenfranchising Alma by lying to her about the family meeting start time and sneaking around her to guarantee their predetermined outcome? Might the team's decision to disenfranchise Alma have been prevented by the simple awareness of accountability?

The disenfranchisement of African American patients and families is not limited to end-of-life decisions. There is similarly tragic disenfranchisement in mental health. Jacob Rock (2021), an African American mental health patient documented his experience at an inpatient mental health farming community. While acknowledging the many positive aspects of such communities, Jacob also suffered at the painful intersection of the kind of racism in SDM unveiled by Peek et al. (2011a & b) and the kind of "silent misdiagnosis" and disenfranchisement of patient preferences brought to light by Mulley et al. (2012).

Having finally found the courage to flee a hellish marriage, Jacob was pathologized by his abusive wife as delusional for questioning her character and ultimately leaving the home. His pathologization as delusional was supported by Jacob's own parents who refused to conscience divorce as an acceptable outcome for their good Christian son and cooperated in lockstep with his wife's diabolical schemes. Having experienced how much power family members can wield through mental health mechanisms, aided by law enforcement, Jacob ultimately succumbed to their aggression and struck a deal with his parents to spend time at an inpatient healing farm community in exchange for their payment of some outstanding bills.

Jacob hoped that on this healing farm, he might find advocates who believed his story and vindicated his experience of an abusive marriage. He certainly had no trouble finding a plethora of whole-hearted supporters for his divorce, whether for good reason or not. But he did not find anyone interested in understanding him through a lens of anything other than the prepackaged label of delusional disorder that his parents admitted him with. There was, however, one exception. Jacob connected with a nurse who after listening to his story, uttered three simple words that finally made him feel seen for the first time:

"I believe you," she said.

Jacob swallowed hard, holding back a floodgate of tears as there was very little privacy in the nurses' group office. He barely managed to hold himself together while getting out the words, "that means a lot."

Following his conversation with the nurse, Jacob made it known to his therapeutic team both verbally and in writing on multiple occasions over a three-week period that he planned for the nurse to join the team on the phone call for his disclosure of his final divorce decision to his parents. While not heavily engaged, his plan was verbally acknowledged, and so, he assumed, agreed to, especially since he received no written responses to the contrary of his written declarations.

The morning of the fateful call, however, the team got together, decided amongst themselves that, from their perspective, the nurse was not relevant to the call, and promptly uninvited the nurse from

the call without mentioning anything to Jacob. They proceeded to ignore Jacob's written text message (that they were copied on just hours later), where he informed the nurse of the time and place for the call. Then, when he arrived at their office for the call, they simply said that "something came up" and the nurse "couldn't make it."

Like Alma with her husband of 40 years on his deathbed, Jacob too, with the rage of his parents' impending harsh judgement on the horizon, was disenfranchised by the clinical team from the conversation that mattered most. His only true advocate was unilaterally uninvited, and he was considered either incapable or unworthy of involvement in a shared decision for who to include on one of the most important and difficult phone calls of his entire life.

To make matters worse, among other slights, Jacob was incessantly disparaged and actively sabotaged by the white master of the farm work program (with his designer farm-chic flannels and flashy boots) that Jacob and his peers were compelled to labor for Mondays through Fridays to earn participation points for more affordable and flexible accommodations in the step-down program. At first Jacob thought that the farm master just hadn't gotten to know him yet, innocently assumed Jacob was just another lazy patient who would truly benefit from being whipped into shape, and genuinely wanted to inspire a healthy work ethic.

But sharing with the master his dogged pursuit of entrepreneurial projects and published academic work, to which he preferred to devote a significant portion of his working time, did not earn Jacob the favor he anticipated. Rather, the disclosure of his tireless work ethic, and the important causes to which he was committed, mysteriously set the master further against him in what felt like a curiously deep-seeded rivalry between his independent agency and the master's need for dominance and servile submission.

Jacob's ultimate conclusion from his inpatient experience on a "healing farm"? "I am 'just a slave' on their plantation" (Rock, 2021).

While African Americans like Alma and Jacob are not the only vulnerable patients victimized by chronic systemic failures in shared decision making, African Americans are, as in most every other arena in American society, uniquely vulnerable and uniquely victimized. Just as blacks were uniquely exposed to harsh research conditions pre-IRB (through Tuskegee and the like), they again stand to benefit the most from ethical oversight for communication accountability. Therefore, the SDM innovations here proposed are yet another example of the many demands we should all be making in the #BlackLivesMatter movement. In the words of Martin Luther King: "Since we know that the system will not change the rules, we are going to have to change the system." As we have seen in Alma's EOL SDM disenfranchisement and Jacob's inpatient mental health SDM disenfranchisement, healthcare is fundamentally about responding to another's hope, and, in the words of a "BLM for healthcare" Facebook group: "Black Hopes Matter" (BHM, 2021). Or at least black hopes should start to matter to someone other than black patients and families, much more than they too often currently do. This is not to say that all white clinicians are racist; but it is to say that there may be more patients and families than we realize who feel like healthcare has put a knee to their neck, making it hard for them to breathe. As Sheila P. Davis and Gary Davis evidenced and characterized it, there are patients and families who identify as "the 'George Floyd' of healthcare" (Davis & Davis, 2020). A graphic depiction of this provocative characterization can be found in the "Black Hopes Matter" Facebook group and accessed intuitively at [BLMforHealthcare.com](https://www.facebook.com/BLMforHealthcare) (BHM, 2021).

IRB's achieved accountability for research by inserting an ethical accountability hurdle in front of every proposed research study. Because doctor-patient/family communication is not a controlled environment like research, there is no way to ensure the kind of ethical accountability IRBs ensure for research without live-manning each critical conversation. Combining learning from the pursuit of justice via research IRBs and police body cams, the healthcare notary may be the best next step in pursuit of justice in physician-patient/family communication surrounding vital healthcare decisions. Patient

preferences **matter**, black lives and black hopes **matter**, and the fact that black lives are uniquely susceptible to silent misdiagnosis and mistreatment through disenfranchisement of patient preferences **matters**.

Most cutting-edge innovations in healthcare require novel development of new things (think drugs and devices). But two of the most promising innovations for the future of healthcare communication, especially at the end of life, simply require pulling the chaplain and notary off the bench and inserting them into the starting lineup.

Continuing the basketball analogy for a moment, if physicians are already the heroic Michael Jordan's of medicine, would communication with patients and families really improve if we had two additional role players to round out a proper SDM Triangle?

Chronicling the history of the Jordan era in basketball, ESPN series, *The Last Dance*, showed Bulls coach, Doug Collins saying, "Get the ball to Michael and everybody else get the f*** out of the way" (Hehir, 2020). Perhaps this is how we have approached SDM as a physician-only game. Understandably so. Like Michael Jordan, most physicians perform heroically in nearly everything they do; we all know it takes more than a slouch to get through organic chemistry alone. So it should be no surprise that, just like Jordan was a highly celebrated individual performer before ever winning the NBA playoffs, physicians, too, receive the utmost respect in medicine by virtue of their role as captains of the healthcare team. Whether they are able to bring the best out of interdisciplinary team role players or not, physicians are duly celebrated for their individual performances, without which healthcare fans would indeed have virtually no reason to show up for the game.

But many patients and families are hoping for more out of healthcare than they are getting from the combined strengths and weaknesses of individual physician performances. Like Chicagoans hungry for a championship, they are looking for an outcome that may be unachievable by one star player alone, as heroic as he might be. But advocating for patient and family voices is not an easy task. There are always powerful forces standing in the way of meaningful change. Just ask Tex Winter, a 1980s assistant coach for the Chicago Bulls. Master-minder of the "Triangle offense," Winter was brought in by General Manager, Jerry Krause, to revolutionize the Bulls' approach to teamwork. But head coach, Doug Collins, wasn't having it. Tired of Winter's constant advocacy for an evolution beyond his "just get the ball to Michael" approach, Collins ultimately banned Winter from the bench for games and relegated him to somewhere "off in the corner during practice" (Notelovitz, 2020, p. 1).

But Jerry Krause had the vision and the nerve to fire Jordan's beloved Coach Collins and replace him with assistant coach, Phil Jackson, who was eagerly soaking up Winter's wisdom in the trenches. Where did Krause get the courage to make such a bold move to upset the existing apple cart? The story goes like this:

Krause eventually pulled the trigger in 1989, after Collins had led a young Bulls team to the Eastern Conference Finals.

"Jerry wanted to talk to me," Jordan says. "... He says, 'I may have to do something that's going to rock this franchise.'

"So I say, 'What?'"

"He says, 'I'm going to have to fire Doug Collins.'"

"So I say, 'It's going to [take] some f***ing balls to fire a guy who just took us to the Eastern Conference Finals'" (Notelovitz, 2020, p. 1).

While I lack the recognized authority of a Jerry Krause (and parenthetically, I hope to be a little easier to get along with), I dream of having a similar, if humbler and less authoritative, conversation with physicians in this country, like Jerry had with Michael when he said, "I may have to do something that's going to rock this franchise." In my case, however, I would simply like to suggest something that has the potential to rock status quo physician-patient/family communication surrounding healthcare decisions. I want to share my vision for an SDM "Triangle offense" via Medical Grand Rounds presentations

(Stonestreet, 2020), and solicit physician feedback, among others (including nurses, social workers, chaplains, and more).

I am well aware that this is no small undertaking.

In discussing an earlier draft of this article with a dear friend who happens to be one of the nation's leading bioethicists, I first met resistance, but ultimately found enthusiastic favor for this vision for the future of EOL SDM and beyond. But when my friend and colleague finally came around to my way of thinking, he suddenly exclaimed: "I would not want to be in your shoes when you present this.... One thing you're going to need to prepare for is this: while some of these docs may give you a real hearing and take your ideas at face value, others are just going to say: Who the f*** are you?"

No doubt, in the caste system of modern medicine, chaplains are Shudras and physicians are Brahmins, whether I have a Ph.D. combining the fields of health communication and interdisciplinary arts or not. No matter. Organic chemistry is modernity's unacknowledged ritual incantation conferring secular priesthood. No organic chemistry on my transcript means no status, no voice, no platform in healthcare. I get all that. But those for whom I advocate (and that includes physicians³) are well worth a long series of conversations where I may often feel like Rocky on the ropes against the towering Russian, Ivan Drago.

Change is difficult and painful for all of us, especially for those in power who feel understandably threatened by new proposals. But disproportional power is not always liberating. It can sometimes be exhausting and unnerving. Just ask Jordan now if he can imagine lasting as long as he did with the Bulls under a Collins-style offense without burning out, as many physicians these days are apt to do. Too long unqualifiedly adulated as the infallible popes of modern secularism, well-meaning physicians have been done a great disservice by being placed on a false pedestal that tragically permitted them to silently slip through the communication cracks of ethical oversight. The only people more to be pitied than the physicians themselves, most of whom do their absolute best to live up to false assumptions and unrealistic expectations, are the patients and families who daily suffer the casualties of a tragic lack of systemic accountability for ethical communication. The truth is that deep down, everyone is equally dissatisfied with the status quo, and whether yet consciously or not, ultimately yearning for change.

Like both Jordan and all Chicago Bulls basketball fans of the 1980s, physicians, patients, and families all want the same thing: a win-win team effort for Shared [Medical] Decision Making (SDM) that does not zap, drain, or disenfranchise anyone involved. Perhaps like physicians reading this article now, or attending my Grand Rounds presentations (Stonestreet, 2020), Michael Jordan himself confessed he was more comfortable with the Doug Collins approach to team efforts. Pointing out that while there may not be an "I" in team, there is indeed an "I" in "WIN," Jordan was initially more than a little leery of Phil Jackson's "Triangle offense" (Hehir, 2020). Quite understandably, as Jordan put it in *The Last Dance*, he was uneasy with any approach that amounted to taking the ball out of his hands. As one article reported, "MJ thought it was 'f***ing bulls***' at first. The 'Triangle' nearly tore Chicago apart before it worked" (Notelovitz 2020, 1). Might physicians go through a similar evolution as Jordan did before ultimately coming to grips with a triangle offense for SDM?

Medical researchers (whether Tuskegee types or self-regulating paradigms of ethics), no doubt, felt the same way about the IRB as Jordan felt about the Triangle offense. But for research ethics, history shows that the IRB proved helpful, no matter how annoying it first may have seemed to researchers adjusting to the change. Similarly for basketball:

[T]he system allowed Pippen to take the next step as a scorer and playmaker, and Jordan eventually came to terms with it.

³ Physicians' silent suffering in the status quo is much underestimated (Ofri, 2013). When these measures achieve their destined win-win for all involved, I envision tremendous emotional release for unburdened physicians treasuring the victory like Jordan huddled in the corner, cradling that first championship trophy, bawling his eyes out in psychic relief...

The Bulls came up just short in 1990. But by 1991, Chicago, using Jackson's system, was the best team in the league.

Jackson went on to coach the Los Angeles Lakers — with Winter as an assistant — to five titles in the 2000s using the same philosophy (Notelovitz 2020, 1).

Might we hope for a similar victory and future for EOL SDM and beyond if we implement a new "Triangle offense" for shared medical decision making?

As described by Phil Jackson, "The 'Triangle' offence is set so there's a key pass that creates motion, and then there's 33 different types of options that come out of that single pass" (Notelovitz 2020, 1). Could the above suggested physician's pass to the chaplain for unpacking of patient/family emotions, meaning, story, and values be that first pass in the "Triangle offense" for SDM? And might that pass generate different options, whether 3 or 33, beyond the standard scientific imperative? As we learned above from Gawande's confession, the kneejerk scientific imperative is too often dishonest, irrational, and physically and/or emotionally harmful. And if that's not enough, it is also, by the way, financially costly to the tune of being systemically unsustainable. That is a lose-lose for everyone involved. Dr. Gawande has to sleep at night regretting his "complete lie" and the grave harm it caused the Monopoli family during the tenderest moments of their life together on this earth. Years later, Rich Monopoli still grieves with tears how the ill-advised chemo made his wife, Sara, "sicker, and sicker, and sicker" to the point that she became "so weak" that she could no longer hold her daughter, Vivian. All this while chasing after an ephemeral scientific impossibility unconscionably encouraged by a Harvard physician whose narrative seems to suggest that his emotions may have gotten in the way of clearly communicating his self-suppressed scientific knowledge. In his own words, lest we forget: "I knew it was a complete lie. I just was wanting something positive to say."

Meanwhile, this ill-advised treatment came at a financial cost, both to the Monopoli family, and also to an increasingly unsustainable healthcare system. In other words, this regrettably harmful treatment ultimately materialized into higher healthcare premiums for all of us. I am not an accountant like my esteemed father (who was kind enough to remind me of that shortcoming the day I graduated from college with a supposedly useless communication degree, and not one accounting class to show for my four wasted years as an undergraduate). But with that full disclosure of how financially ignorant and naive I may be, I am still going to go out on a limb here and venture a calculated guess that I invite anyone with greater financial acumen to kindly correct:

Could it be that the cost of 15 minutes of a remote notary's time to be a virtual elephant in the room during Dr. Gawande's conversation with the Monopolis...could that cost for 15 minutes of the remote notary's time have been somewhat more affordable to both the Monopoli family and to all the rest of us (paying resultant insurance premiums) than those last scientifically ill-advised rounds of chemo?

If the reader can humor me for a moment, I wish to take the liberty of engaging in a mental exercise to try to begin to fathom the gravity of the context that we are grappling with, for the future of healthcare communication. Here it is again in case anyone missed it: what we are doing here is we are laying two costs on opposing sides of an old-school analogue scale like the one that the Olesen's used to measure out grain in their Mercantile store in the old-time television show, *Little House on the Prairie*. Our task is to try to imagine which way the scale will tip when we place two different hypothetical healthcare costs on opposing sides (can you believe I am doing such a complicated calculation without any accounting training, Dad?). On one side of the scale, we have the cost of multiple weeks of experimental chemotherapy. On the other side of the scale, we have the cost of 15 minutes of a remote-notary's time.

Can someone with an accounting degree please help me out here? Let's place both of these approximate, hypothetical costs on the scale and see which way it tips. I will leave the accounting work to those with useful college training. My only purpose here is to articulate a vision and share it with you.

I don't know about you, but I will tell you what just happened in my mind when I placed those two costs on either side of that old scale. I just got the mental image of the chemo side of the scale dropping so hard and fast that it broke a hole through the counter beneath the scale, and then it broke another hole through the flooring underneath the counter. At the same time, I am imagining the notary's 15-minute fee catapulting high up into the air from the other side of the scale.

And all of this while the Monopoli family gets to focus on saying goodbye while maximizing the quality and comfort of their final weeks together with Sara. Again, lest we forget Rich's narrative, it was precisely that ill-advised round of chemo that so tragically and so prematurely forced dear little Vivian out of a dying Sara's arms. So Sara is now cradling little Vivian in her arms for days or weeks longer than she was otherwise able to.

As hard as I was laughing while writing that exaggeratedly humorous scale-narrative in the previous paragraph, I kid you not, I am now weeping as I imagine the Monopoli family having a profoundly different experience and memory of Sara's death. Please listen to me, dear reader. This is so important.

Rarely are emotional/spiritual and financial realities so conveniently aligned. How then can we, in good conscience, let the status quo continue, unchallenged?

At the risk of inflaming the culture wars and our ever more rabidly partisan politics, I want to make a politically-agnostic (I promise!) observation that simply cannot be avoided after invoking the rhetoric of healthcare sustainability as it relates to end-of-life treatment decisions. Regardless of its source, or the specificity of its facticity, the 2009 cry against government healthcare "death panels," infamously heard around the world, was rooted in the fear of pursuing healthcare sustainability in ways that threatened individual liberty. But what I am suggesting here turns that needlessly false juxtaposition on its head. Rather than pursuing healthcare sustainability in ways that might regrettably decrease individual liberty, might we instead be paradoxically positioned to pursue individual healthcare liberties in ways that conveniently increase systemic sustainability?

It sure seems that way to me as I contemplate the realities depicted by PBS Frontline's Gawande-Monopoli narrative. Perhaps the Monopoli family didn't need a (hypothetically feared) "panel" of government experts to tell them that they were not allowed to have that final round of futile chemo. Even if that (hypothetical) panel were correct, the bureaucratic strong-arming disenfranchisement of their hopes could arguably have ended up hurting the family just as bad, or God-forbid, even worse than the ill-advised chemo did. Alma can explain to you precisely what I mean by that! -- both verbally (Alma, 2020), and in writing (Stonestreet, 2021).

Perhaps all the family really needed was ethical healthcare communication. Could it be that simply creating and holding the communicative space necessary for patients and families to devote a greater attentiveness to our own spiritual values will naturally lead (on aggregate) to the most sustainable future for this particular aspect of healthcare than any of us could ever otherwise begin to imagine? I sure would love to hear what Rich Monopoli thinks of this suggestion.

While this suggestion would, sadly, only be a hypothetical for the Monopoli family, I believe it is very much more than a mere hypothetical thought exercise or pipe dream for the future of healthcare. Because it just so happens that if my neanderthal accounting intuitions are even remotely accurate, then private market forces could very feasibly be configured to provision for the ethical communication justice that the Monopoli family so desperately needed. We may not all cherish the image of (so-called/imagined) government "death panels" deciding for us which treatments are appropriate and ethical (and, for the record, I may be America's last-remaining political agnostic, and I am not, I repeat, I am not venturing into the political waters of alleging whether or not "death panels" were ever even proposed by Obama or, for that matter, were ever even envisioned by Hillary, or Elizabeth, or Bernie, or anyone). But while we might not all agree on every externally-imposed approach to healthcare sustainability, perhaps we can all agree on certain systemically-facilitated process innovations that

increase individual liberty...especially if those innovations simultaneously increase social justice and also (in aggregate) increase systemic sustainability.

Wouldn't that tick all the political boxes and just maybe constitute one singular issue around which America can exhale some angst and luxuriate in the momentary cease-fire of a truly bipartisan solution to a problem affecting everyone?

I believe the innovations here proposed may have global implications. However, my tent is currently pitched in America, and that is the context in which I am presently imagining this endeavor. So to my fellow citizens, here is one of the things I think about when I recall saying the Pledge of Allegiance to the American flag in elementary school: Our pledge ends with "liberty and justice for all." Perhaps there is something healthy about the political tension (as increasingly distasteful as it might be these days) between the "right's" focus on liberty and the "left's" focus on justice. But regardless of that tension, or perhaps out of profound respect for it, our goal here is to treat that particular scale (measuring that political tension between liberty and justice) very differently than we treated the poor old mercantile scale we left in shambles with our mental exercise above.

Our goal here is to perfectly balance liberty and justice in such a way as not to anger approximately half of the country, or in other words, not to incur the wrath of either one of the two opposing armies that currently constitute America's present, seemingly impending (metaphorically if not literally) Civil [social/cultural/political] War. Our goal here is to keep that particular scale measuring liberty and justice as perfectly balanced as humanly possible for the surgical enactment of the specific provisions suggested herein.

To use another word picture for our goal, we are simply trying to slide one small piece out of healthcare's Jenga structure without upsetting the balance. Or, if you prefer, depending on your age and your gaming proclivities, we are trying to add just one small and perfectly sized piece to the game of healthcare Tetris. Then we will gladly depart the scene altogether and leave it to the two opposing political armies to fight out the rest of the healthcare war. What we are here seeking is a win-win for all involved, a solution so surgical and so subtle that it functions like a comforting mist in the air for each of the opposing armies gutting out the policy wars in the heat of political battle.

Regardless of what does or does not happen with all of the other politics surrounding healthcare, could a Triangle Offense for Shared [Medical] Decision Making (SDM) increase both liberty and justice for all? Might everyone benefit from government cooperation with new processes implemented and run by private parties to ensure greater patient/family liberty and justice in healthcare decision making?

As ambitious as this might be, I am truly interested in pursuing politically agnostic solutions that are equally suitable and satisfactory to all parties. So, given my above invocation of government "cooperation," I can only imagine that some on the "right" might ask why it would even be necessary to involve the government at all. To that, I would only point out that (regardless of anyone's political opinion on the matter), for better or for worse, the government is already a multi-trillion-dollar player/payor in healthcare (and has been now for more than five decades).

Namely, it is the Medicare budget that has the most to gain (on the front end) from helping us all to arrange for a world in which our imagined analogue scale catapults that 15-minute notary fee up into the stratosphere in exchange for the comparatively astronomical emotional and financial cost of that ill-advised experimental chemo treatment for Sara Monopoli. In other words, we just want to collaborate with the government in some relatively quick and easy duct-taping and/or velcroing together of the appropriate existing, moving systemic parts, in such a way that they will functionally allow existing market forces to better flow through existing channels in furtherance of healthcare's "quadruple aim" (Sikka et al., 2015): care, health, cost, and meaning. At the risk of oversimplification, let's use the narratives we have been exploring to imagine the "quadruple aim" impact of the proposals at hand. Here are some of the kinds of things that I believe could happen in a world where these ideas become a reality:

1. The Monopoli family gets the truth out of Dr. Atul Gawande when he gets a second shot at the difficult task of breaking bad news, and
2. Rich and Sara Monopoli get to acknowledge the reality of what is happening in time to savor their final weeks together as a family, and say a proper goodbye, and
3. Sara Monopoli is cradling baby Vivian in her arms a little easier and a little longer, and
4. Dr. Atul Gawande is sleeping better at night for having hit that second pitch, provided by the notary, out of the park and telling that hard truth he so yearned to tell, and
5. Alma, who was tempted to charge her already overloaded credit card for another carton of cigarettes and bag of unhealthy snacks, in search of comfort, as she despaired over the loss of her husband and the loneliness of being a prisoner in her own home in fear of COVID-19, spends that money instead on becoming a virtual healthcare notary from the comfort and safety of her own, now meaning-infused home office, and
6. Alma's motivation for becoming a healthcare notary is based on the personal experience of being disenfranchised, and seeing her dying husband disenfranchised from what should have been an ethical process of Shared Decision Making, and
7. Alma's first client case as a healthcare notary is for a woman by the name of Sara Monopoli, who together with her husband, Rich, is unknowingly facing an unfathomably sad ending to their bright, young family's hopes and dreams, and
8. Alma's suffering from the unethical communication that complicated her grief over her husband's death is somewhat redeemed by her intervention with Dr. Gawande on the Monopolis' behalf, and
9. Alma's second case as a healthcare notary is for a pilot program in inpatient mental health, where she again redeems her own suffering by helping to protect a middle-aged black man named Jacob from being further disenfranchised from a shared decision on his journey of recovering from years of heinous spousal abuse while being tragically misunderstood and judged by his own family and friends, so that he could feel like a little less of a "slave" on that "healing farm" "plantation," and
10. As a result of each of these interventions:
 - a. the financial resources that were wasted on Sara Monopoli's last rounds of ill-advised experimental chemo paid instead for:
 - i. Sara Monopol's hospice comfort care, spiritual care, legacy building, and music therapy services
 - ii. Alma's notary service fee and renewed life's purpose as a social justice entrepreneur in healthcare
 - iii. A financial kickback (justified by Value-Based-Care, as opposed to Fee-for-Service) goes to:
 1. Dr. Atul Gawande, and
 2. The hospital Gawande was serving in, and
 3. The experimental chemo company that did not enroll Sara
 - b. The experimental chemo company that hypothetically stands to lose some of its margin in the Monopoli's case turns out to be a winner on several counts in the end because
 - i. The experimental chemo will be proven more effective and thus more valuable because "false negatives" like Sara will no longer skew the research outcomes in a negative direction for the chemo trial. Think about it: When Sara Monopoli is ill-advised by Dr. Gawande to enroll in that last chemo trial, the fact that she was already doomed to die (as Gawande later admitted), regardless of the efficacy of the experimental chemo, means that it might be short-sighted of the chemo maker to covet her participation in that trial. Here's why: Sara's participation in

the chemo trial threatened the success of the trial itself. Why would the chemo maker want someone who is doomed to die thrown into their experiment on whether or not their drug can save or prolong lives?

- ii. In the final analysis, the chemo company also wins in other ways. Good karma brings other related savings from types of cases. For example, Alma's altered trajectory of fewer emergency room visits gives Medicare and Medicaid more margin for (previously rejected) reimbursements for a greater number of more medically appropriate patients, who actually benefit greatly from the experimental chemo, boosting its market value.
- c. The many hundreds of thousands of dollars that Medicaid and Medicare have spent on Alma's physical and mental healthcare over the years, as a result of the psychosomatic outcomes of her complicated grief over the unethical communication and related disenfranchisement that tipped her over the proverbial edge in the years following her husband's death
 - i. Could have been prevented altogether if an African American notary had accompanied Alma's husband in a recorded conversation with his healthcare team surrounding his hospice transfer, or
 - ii. Even in a world where Alma's disenfranchisement and related suffering was somehow unpreventable, her related psychosomatically-rooted healthcare costs would be substantially if not drastically reduced by the redemption of Alma's suffering through her social justice entrepreneurship as a healthcare notary. Alma experiences multi-valent healing through the gratification of being able to provide the kind of communication facilitation assistance to others that was tragically unavailable to her, and this redemption of her suffering leads to psychosomatic transformation of her physical and mental health, dramatically reducing her healthcare utilization and costs over the decades since her disenfranchisement.
 - iii. This tremendous financial savings for Medicaid, and later Medicare, would allow the programs to pay for better care to more recipients, charge tax payers less for the care provided, and still provide more and greater reimbursements for experimental therapies like that same chemo that the wealthier, white Monopoli family didn't need, but that could have greatly benefited more appropriately disease-process-matched, (and coincidentally) poorer (including disproportionate numbers of black, and other minority), patients and families who now benefit from greater access to early stage experimental therapies.
 - iv. In other words, as "too good to be true" as it might sound, there really are no losers in this proposed improvement in ethical communication and accountability surrounding healthcare decision making. Ethical communication for better healthcare decision making is truly a win-win for every imaginable interested party.

Coming back down to earth from that fanciful thought exercise, my question to both sides of America's political/social/cultural wars is this: Who wouldn't want more clarity, honesty, and sophistication in the critical interpersonal communication surrounding major healthcare decisions? More than anything, this is simply about creating and holding space for more intentionality and reflectiveness in the sometimes complex and challenging task of healthcare decision-making. What could be more fundamental to the ethos of healthcare than being empowered to more fully engage with caregivers to ultimately decide for ourselves which services are best for our own lives and the lives of our families?

In the introduction to this article, I showed how a notary could have assisted in the Gawande-Monopoli conversation in such a way that it would have most likely prevented Gawande's blunder and also resulted in a very different outcome for all involved. At the very least, there could have been a fair and clear disclosure and consideration of the various options available to Sara in a more ethical process of Shared Decision Making (SDM).

Is what I am suggesting feasible? Will it really work? Can Phil Jackson's Triangle Offense create victories for the Bulls, the Lakers, and the future of Shared Decision Making (SDM) for healthcare communication? Only time will tell.

Who wants to step up and collaborate with me to give it a try and see what happens?

Together, may we work toward a brighter future for everyone involved in, and impacted by, high-stakes communication surrounding healthcare decision-making. The road may not be easy. But our work will be worth every ounce of our effort. Just ask Dr. Gawande, husband Rich, patient Jacob, and wife Alma.

REFERENCES

- Alma (2020). *Alma Speaks*. AlmaSpeaks.com. <https://www.youtube.com/watch?v=HtuhIkRKJko>
- Altman, A. (2015). *Black lives matter: A new civil rights movement is turning a protest cry into a political force*. Time Magazine. <https://time.com/time-person-of-the-year-2015-runner-up-black-lives-matter/>
- Back, A., Arnold, R., & Tulskey, J. (2021). *VitalTalk Makes Communication Skills for Serious Illness Learnable*. VitalTalk. www.VitalTalk.org
- BHM (2021). *Black hopes matter (BHM)*. BlackHopesMatter.com. Facebook Group. <http://www.facebook.com/BlackHopesMatter>
- Bishop, J. (2011). *The anticipatory corpse: Medicine, power, and the care of the dying*. University of Notre Dame Press.
- Boland, L., Graham, I. D., Legare, F., Lewis, J., Shepherd, A., Lawson, M. L., Davis, A., Yameogo, A., & Stacy, D. (2019). Barriers and facilitators of pediatric shared decision-making: A systematic review. *Implementation Science* 14(1), 7. <https://doi.org/10.1186/s13012-018-0851-5>
- Brown, J. (2015). *The case for body cameras: Good for doctors — and their patients — why one doctor wants to see a camera added to a clinician's equipment checklist*. Medpage Today. <https://www.medpagetoday.com/opinion/epmonthly/50492>
- Cadge, W., Calle, K., & Dillinger, J. (2011). What do chaplains contribute to large academic hospitals? The perspectives of pediatric physicians and chaplains. *Journal of Religion and Health* 50(2), 300-12. <https://doi.org/10.1007/s10943-011-9474-8>
- Davis, S. P., & Davis, G. (2020). The George Floyd of healthcare. *Journal of Health Ethics*, 16(2). <http://dx.doi.org/10.18785/ojhe.1602.07>
- Elwyn, G., Durand, M. A., Song, J., Aarts, J., Barr, P. J., Berger, Z., Cochran, N., Frosch, D., Galasinski, D., Gulbrandsen, P., Han, P. K. J., Harter, M., Kinnersley, P., Lloyd, A., Mishra, M., Perestelo-Perez, L., Scholl, I., Tomori, K., Trevena, L., ... Van der Weijden, T. (2017). A three-talk model for shared decision making: multistage consultation process. *British Medical Journal* 359(j4891). <https://doi.org/10.1136/bmj.j4891>
- Elwyn, G., Frosch, D. L., & Kobrin, S. (2016). Implementing shared decision-making: Consider all the consequences. *Implement Sci*. 11(114). <https://doi.org/10.1186/s13012-016-0480-9>
- Fried, T. R. (2019). Communication about treatment options and shared decision making in the intensive care unit. *JAMA Internal Medicine* 179(5), 684-685. <https://doi.org/10.1001/jamainternmed.2019.0034>
- Gawande, A. (2015). *Being mortal*. PBS Frontline. <https://www.pbs.org/wgbh/frontline/film/being->

mortal/

- Gawande, A. (2021). *Serious illness care*. Ariadne Labs. <https://www.ariadnelabs.org/serious-illness-care/>.
- Hehir, J. (2020). *The last dance*. ESPN. <https://www.netflix.com/title/80203144>
- Hughes, B., Witner, M., & Hurst, S. (2007). Innovative solutions: A plurality of vision: Integrating the chaplain into the critical care unit. *Dimensions of Critical Care Nursing* 26(6), 91-95. <https://doi.org/10.1097/01.DCC.0000267801.62949.6d>
- Kim, K., Heinze, K., Xu, J., Kurtz, M., Park, H., Foradori, M., & Nolan, M. T. (2018). Theories of health care decision making at the end of life: A meta-ethnography. *Western Journal of Nursing Research* 40(12), 1861-1884. <https://doi.org/10.1177/0193945917723010>
- Kunneman, M., & Montori, V. M. (2017). When patient-centered care is worth doing well: Informed consent or shared decision-making. *BMJ Quality & Safety* 26(7), 522-524. <https://doi.org/10.1136/bmjqs-2016-005969>
- Kuziemsky, C. E., Borycki, E. M., Purkis, M. E., Black, F., Boyle, M., Cloutier-Fisher, D., Fox, L. A., MacKenzie, P., Syme, A., Tschanz, C., Wainwright, W., Wong, H., & Interprofessional Practices Team (alphabetically). (2009). An interdisciplinary team communication framework and its application to healthcare 'e-teams' systems design. *BMC Medical Informatics and Decision Making* 9(43). <https://doi.org/10.1186/1472-6947-9-43>
- Marin, D. B., Sharmna, V., Sosunov, E., Goldstein, R., & Handzo, G. F. (2015). Relationship between chaplain visits and patient satisfaction. *Journal of Health Care Chaplaincy* 21(1), 14-24. <https://doi.org/10.1080/08854726.2014.981417>
- Matsakis, L. (2020). *Body cameras haven't stopped police brutality. Here's why*. Wired. <https://www.wired.com/story/body-cameras-stopped-police-brutality-george-floyd/>
- Mulley, A. G., Trimble, C. & Elwyn, G. (2012). Stop the silent misdiagnosis: Patients' preferences matter. *British Medical Journal* 345(e6572). <https://doi.org/10.1136/bmj.e6572>
- Nedjat-Haiem, F. R., Carrion, I. V., Gonzalez, K., Ell, K., Thompson, B. & Mishra, S. I. (2017). Exploring health care providers' views about initiating end-of-life care communication. *American Journal of Hospice & Palliative Care* 34(4), 308-17. <https://doi.org/10.1177/1049909115627773>
- Notelovitz, G. (2020). *MJ thought it was "f***ing bulls***" at first. The 'triangle' nearly tore Chicago apart before it worked*. Fox Sports. <https://www.foxsports.com.au/basketball/nba/mj-thought-it-was-fing-bulls-at-first-the-triangle-nearly-tore-chicago-apart-before-it-worked/news-story/8074ad5068cbfbf1ccc8e327ae5ff9d2>
- Ofri, D. (2013). *What doctors feel: How emotions affect the practice of medicine*. Beacon Press.
- Peek, M. E., Odoms-Young, A., Quinn, M. T., Gorawara-Bhat, R., Wilson, S. C., & Chin, M. H. (2010a). Race and shared decision-making: Perspectives of African-Americans with diabetes. *Social Science & Medicine* 71(1), 1-9. <https://doi.org/10.1016/j.socscimed.2010.03.014>
- Peek, M. E., Odoms-Young, A., Quinn, M. T., Gorawara-Bhat, R., Wilson, S. C., & Chin, M. H. (2010b). Racism in healthcare: Its relationship to shared decision-making and health disparities: A response to Bradby. *Social Science & Medicine* 71(1), 13-17. <https://doi.org/10.1016/j.socscimed.2010.03.018>
- Pieterse, A. H., Stiggelbout, A. M., & Montori, V. M. (2019). Shared decision making and the importance of time. *JAMA* 322(1), 25-26. <https://doi.org/10.1001/jama.2019.3785>
- Ramsey, P. (1970). *The Patient as Person*. Yale University Press.
- Rock, J. (2021). JustaSlave.com: BLM & #MeToo in healthcare.
- Sikka, R., Morath, J. M., & Leape, L. (2015). The quadruple aim: Care, health, cost and meaning in work. *BMJ Quality & Safety* 24(10), 608-610. <https://doi.org/10.1136/bmjqs-2015-004160>

- Spatz, E. (2021). *Why shared decision making should apply to informed consent*. Mental Health Reform. www.careforyourmind.org
- Stonestreet, J. (2019). Recommendations for how to respond when the family is hoping for a miracle. *Preprints 2019*, 2019050213.
<https://www.preprints.org/manuscript/201905.0213/v1>
- Stonestreet, J. (2020). *Schedule Grand Rounds*. www.DrJohnStonestreet.com
- Stonestreet, J. (2021). For the love of Alma, black hopes matter. *Palliative Medicine Reports* 2(1), 101-103. <https://doi.org/10.1089/pmr.2020.0018>
- The, A. M., Hak, T., Koeter, G., & van der Wal, G. (2001). Collusion in doctor-patient communication about imminent death: An ethnographic study. *British Medical Journal* 323(7282), 247-53. [10.1136/ewjm.174.4.247](https://doi.org/10.1136/ewjm.174.4.247)
- Wikipedia. (2009). *Death panels*. https://en.wikipedia.org/wiki/Death_panel.
- Wirpsa, M. J., Johnson, R. E., Bieler, J., Boyken, L., Pugliese, K., Rosencrans, E., & Murphy, P. (2019). Interprofessional models for shared decision making: The role of the health care chaplain. *Journal of Health Care Chaplaincy* 25(1), 20-44.
<https://doi.org/10.1080/08854726.2018.1501131>