AN INTENSIVIST DRAWS ON HIS LIFE IN MEDICINE TO RETOOL FOR A VITAL PATIENT SERVICE: 'THE CONVERSATION'

Lessons from the Elephants

ANTHONY M. COSTRINI, MD, MA, FACP

As children, my twin brother and I could not wait to see the latest episode of the Fifties TV show "Ramar of the Jungle," with its adventure, heroism and anticipatory drum beats. One unforgettable episode about the elephant graveyard, where aged members of the herd supposedly went to die, was particularly impressive in teaching 8- or 9-year-olds the fact of universal mortality.

Now in my eighth decade of life, after 50 years of critical care experience, I have been called a silverback by younger physicians. I couldn't help but wonder about the slow amble toward the elephant graveyard: If recognizing and accepting the passage of time is good enough for a wise old elephant, why not a "wise" old internist?

Yet . . . although I may no longer be leading the herd, I am still stepping along at a reasonable pace. Perhaps, I thought, I can find another way to participate in the specialty I love and make the most of my remaining tools.

Thus what started as an effort to prevent brain rust turned into many nights of reading and writing to obtain a Master of Arts degree in bioethics and health care policy. The combination of ethics training and years of membership on our hospital ethics committee, as well as almost 50 years of intensive care experience, give me the basis for a different career track.

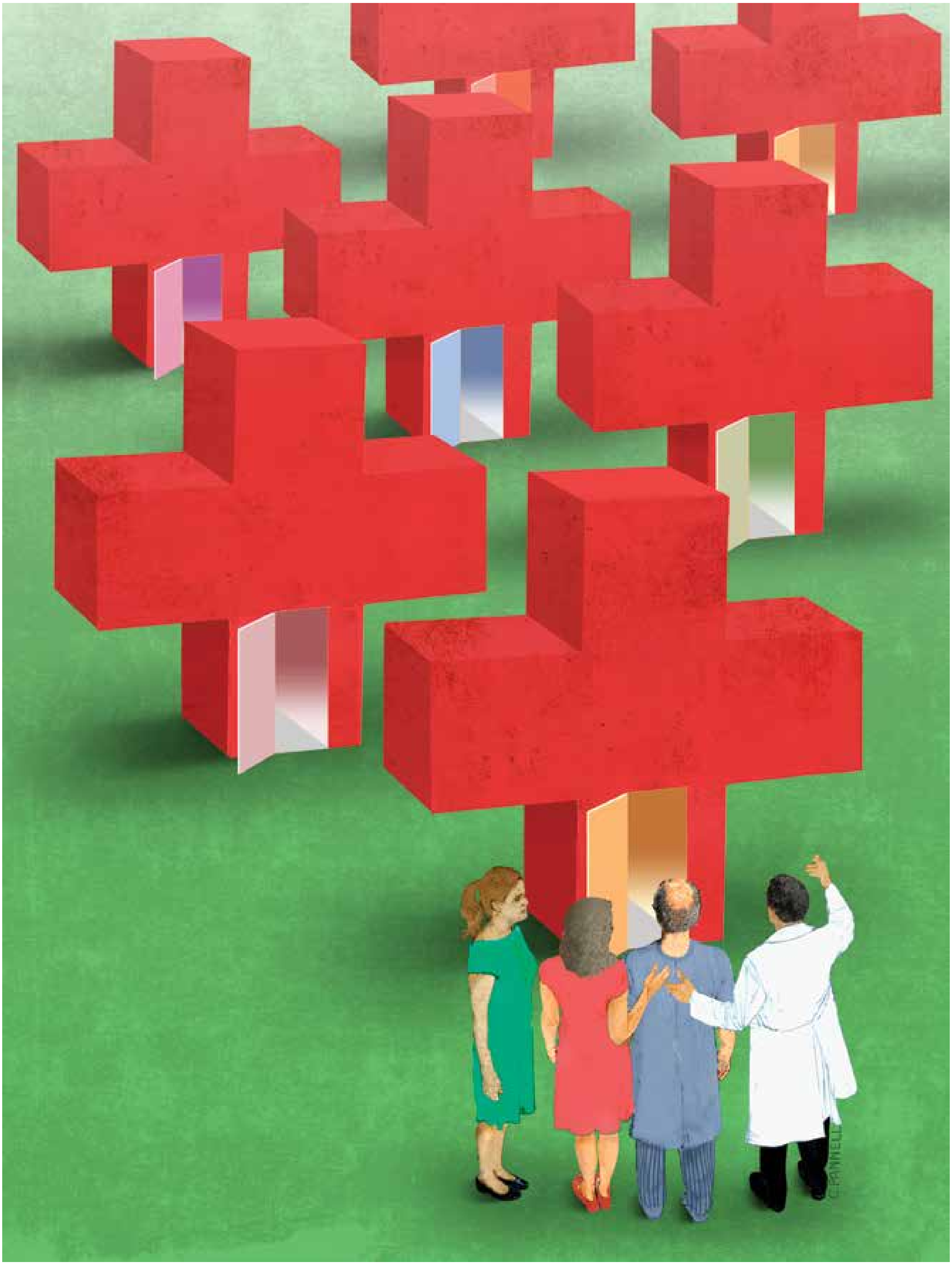
It's one that makes sense for me — and perhaps it would for you, too — because not only does it draw on my experience and training to provide service, it gives me personal and professional satisfaction. I call it "Critical Healthcare Decisions." It encourages doctors and other health care providers, as well as patients and their surrogates, to be active in the process of medical decision-making that will be necessary during a serious illness and near-end-of-life situations.

CHOICES AND GOALS

The inexorable slide from health to illness, to the recognition of the likelihood of death, to the dying process, could be smoother for all of us. The key is earlier, preemptive recognition and acceptance of the natural process of life, which proceeds despite any denial of death. We still have choices we can make along the way, but what if we haven't made our choices clear, or we don't have all the information we need to make decisions that reflect our wishes and values? Or what if we have lost the ability to comprehend or to communicate?

That's where my new endeavor fits in. It builds on a term I coined more than five years ago — preemptive ethics — which is really not so different from initiatives espoused in the well-written books *Being Mortal: Medicine and What Matters in the End*, by Atul Gawande, MD, and *The Conversation*, by Angelo Volandes, MD.[1, 2] Both encourage doctors and other health care providers, as well as patients, to be active in the end-of-life decision-making process.

That conversation is more important than any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other decision process, and determining what constitutes our best life is our right and responsibility. But how do you conduct such an important discussion, who should be part of it, what do families and patients need to understand about advance directives, designation of a surrogate for medical decisions, Do Not Resuscitate orders and the like? And what if family members and the patient don't agree?

That calls for a Critical Healthcare Decisions consultation. I use an organized, proactive approach to help patients and their surrogates recognize that it is their right — and their responsibility — to determine what constitutes their best life.

That's my first goal, and I draw on my background and experience to help people through the process, ideally before they face making critical decisions at 2 a.m. under conditions of severe stress, distress, fatigue, fear and anger or emotional devastation. But I have found that even in the intensive care unit, it is possible to discuss critical issues with patients and perhaps become a patient advocate in bridging the relationship from the very busy intensivist to the very anxious family and patient.

A second goal is to interact with physicians with whom I have had a relationship for decades, to encourage them to facilitate and communicate with their patients to make health care decisions. This is an effort which, if successful, will make my Critical Healthcare Decisions initiative redundant and no longer necessary. I'm fine with that!

A third goal is to enhance patient awareness through community efforts such as printed articles in local publications, lectures to civic groups such as Rotary, Lions and Kiwanis, as well as talks with potential patients residing in nursing homes

GUIDING CONVERSATIONS ABOUT CRITICAL HEALTH CARE DECISIONS

Who is suited to guide a Critical Healthcare Decisions conversation?

There is no substitute for experience, but there also is no substitute for competency. Implementing a preemptive decision-making program requires a basic understanding of medical ethics, palliative care and hospice care, as well as an awareness of various pertinent documents such as POLST forms, "Five Wishes" and advanced directives.

The literature is vast in these areas and capable of supplementing — and perhaps correcting — concepts learned through years of experience. There are online courses, as well as national meetings, that address these topics. The 2017 international meeting of the American Thoracic Society, for example, provided multiple sessions and voluminous abstracts regarding end-of-life issues.

Some aspects of medical ethics must infuse our conversations with patients and families. The four principles — patient autonomy, beneficence, nonmaleficence and justice — don't change, but the years have brought new ways of optimizing patient care and dignity within the confines of these principles.

For example, most "old timers" began practice in the era of medical paternalism and watched the pendulum swing toward patient autonomy, which at times became absolute. We continue to recognize patient autonomy, but we have entered an era of more formalized shared decision-making. The code of ethics for ethicists encourages consultations to support patients in formulating their own health care wishes without authoritative recommendations that may be viewed as intimidation and reversion to paternalism.

That means when the family or patient asks, as they often do, "What would you do if it was your mother?" the current correct answer is to say, "It is not about my mother. You must make your own decision."

My own view of this, based on experience and reflection upon the role of a consultant, is that when the patient asks for help, it is appropriate to provide a reply that makes choices clear or easier to reach. So in a relationship of trust between patient and physician, it may be reasonable to actually state what your family member did in a similar situation. This provides an opportunity, as well, to provide a realistic picture of the patient's actual situation.

A note to the primary care physician: It may well be that you are the one best suited to guide your patients and their families through these critical discussions. You are known to the patient and, most importantly, trusted. There is no substitute for trust during this difficult, possibly daunting experience. Your knowledge of the patient and his or her culture provides a huge advantage in listening and perhaps helping him or her comprehend health issues and choices to be made about them, consider any relevant family matters and explore the very personal meaning of living well.

or various types of assisted-living arrangements, including retirees in independent living.

A particularly rich area of outreach would be to communicate with concierge physicians who theoretically have two very important ingredients to facilitate the conversation: time and trust.

WHAT THE DISCUSSION COVERS

It clearly is better for everyone when an individual or surrogate has put on record as many health care decisions and directives as possible prior to a serious medical procedure. Consider the prospect of an aortic valve replacement and potential complications for an individual in the tenth decade of life. Any health care provider need only contemplate facing, in the hospital corridor, the stereotypical "son or daughter who just flew in from New York" to appreciate having a document that clearly and thoroughly establishes the patient's wishes.

A Critical Healthcare Decisions consultation is a forward-looking conversation that begins where "informed consent" paperwork ends.

Ideally, the decisions are based on conversations held when there was no health alarm at hand, but the most important thing is this: The decisions should cover potential complications, including death or permanent incapacitation, as well as the nuts and bolts of a short- or long-term stay in the intensive care unit.

Those conversations take some preparation and skill; one resource is the helpful "how-to" article that Keith M. Swetz, MD, and others published in *The Journal of Symptom and Pain Management* to direct clinicians through this important "preparedness planning" process.[3]

In my experience, medical and treatment complications and their implications — especially dire ones — tend to be in the fine print on a form, or are whispered at the end of discussions about permission to operate. The anxious patient waiting to be cured by surgery often doesn't take in the details. It isn't unusual for accompanying family members not to hear, understand or absorb the details, either.

A Critical Healthcare Decisions consultation is a forward-looking conversation that begins where "informed consent" paperwork ends. In other words, it lays out detailed questions for the patient or surrogate to consider, such as:

- In case things don't go well, do I want CPR?
- Just how long do I want heroics in an ICU if the likelihood of survival or functional recovery is less than 10 percent?
- Do I want emergent or permanent dialysis?
- Do I still want "heroics" if I happen to have a debilitating neurological event? If that were to happen to me, how important is functional life — that is, what physical limitations am I willing to accept if I can't fully recover?

The consultation means explaining the possibility of mechanical ventilation, renal failure, decisions regarding feeding tubes and nursing home placement, as well as other not-at-all-rare complications such as debilitating stroke, or heart rhythm disturbances that raise the question of permanent pacemakers and defibrillators.

There are physicians who insist that discussing such details is a morbid exercise that could hinder an optimal outcome. I have been called a "thief of hope" by an oncologist or two.

Some patients may choose to avoid such conversations because they don't want to consider unpleasant possibilities or details. Delaying such an important discussion because of fear may be a patient's right, but it is a very bad idea, and part of the consultation is to explain why that is. Sometimes it helps to point out the surrogate's dilemma if he or she suddenly becomes the decision-maker without knowing what the patient would wish. Or perhaps disagreements have come to light, making it critically important to undertake a successful patient-family-physician conversation to address the issues before a possible battle of a lifetime.

STEPPING BACK

Let's step back and look at death. It no longer is the private passage of a 60-year-old individual on an isolated farm, miles from his doctor or hospital. Nowadays, individuals might live 80 years or more, they recognize their terminal health state and many decide (with or without a practitioner's input) that they wish to live at home, as comfort-

As I created and practice it, Critical Healthcare Decisions consultations are a “niche” service that is not owned, paid or supported by any hospital. The major goal is to work preemptively prior to hospitalization to ascertain the patient’s vision of his or her own health care journey.

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Fortunately there now are billing codes for advanced health care planning, including modifiers for discussions lasting longer than 35 minutes. Services provided within the hospital can be billed as simple visits.

I have reached out to peer practitioners, asking them to refer patients to me to introduce the concept of health care decision-making that truly reflects the wishes of the patient. I believe it is critical to make use of the trust that has evolved from years of working with peers so that they can facilitate the transfer of their patients’ trust to a consulting physician. Trust is truly a key component of this initiative that encourages a patient to decide and express his or her health care preferences rather than leave critical decisions to close or distant family members — or worse, to no one at all.

Here is an example of how I report back to the referring physician.

Dear Dr. [Name],

Thank you very much for referring Mr. and Mrs. Smith to me for a visit for Critical Healthcare Decisions. They are a delightful couple who have good insight into his disease process. We spent well over 70 minutes and had what I think was a very successful visit.

As you know, he suffers from stage IV lung cancer, which appears to be reasonably stable. He is on Tarceva. There appears to be no reason to stop it. He has lost weight from 240 to approximately 150 pounds and is gradually becoming weaker. He has complicating recurrent aspiration pneumonia. He has sleep apnea but is not currently compliant with his CPAP, stating that he has some mask issues. I have asked him to speak with [company] to fix his mask, particularly if he chooses to proceed with surgery to repair his fractured arm.

He feels that he is competent and capable of making decisions, and his wife agrees. During our visit, I found him to be occasionally slightly confused but, in general, able to communicate very well and to understand nuance in discussion and to exhibit a good sense of humor. He has designated his wife as his health care decision-maker and specifically excludes his children, who he states are not at all involved in his health care. He feels that if he has a cardiac event, that he would like an attempt at resuscitation if there is reasonable chance that he will have successful resuscitation without long-term residual debility. He does not want to spend time in an intensive care unit. He does not want mechanical ventilation. He does not want dialysis, and he is very clear and adamant that he does not want a feeding tube.

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We had a lengthy conversation regarding options to optimize his life. His wife is distressed because she has difficulty caring for him, particularly since he has a fractured right arm, which makes it extremely difficult for him to get out of a wheelchair. For this reason, they feel they would like to proceed with repair of his fractured arm. He understands that it would be reasonable to proceed with surgery, but not to undertake heroic resuscitation should there be an adverse event. He agrees with his orthopedic surgeon that he should not have his minimally symptomatic hernia repair surgery at the same time. I would strongly discourage both operations at the same time. In order for him to live the best life possible, I would agree that arm surgery is very reasonable.

We discussed the appropriate documentation for his decisions. I provided him with documents including “Five Wishes,” as well as a POLST form, and a [state] advanced directive form.

He might be a good candidate for palliative care. I do not think his prognosis is necessarily less than six months. Given his prognosis and his views on CPR, I do not think he needs hospice at this time. Nevertheless, palliative care might be very beneficial for him and very beneficial for his wife, who is clearly becoming challenged by the amount of effort to care for him. I will investigate which palliative care companies provide services in [state].

All in all, I think we had a very nice visit. Please be sure to ask Mr. and Mrs. Smith if they felt that they benefited from this visit. Thank you for trusting me with your patients.

Finally, I would note that Critical Healthcare Decisions consultation is not a one-stop event. I will stay in touch with Mr. and Mrs. Smith.

ably as possible, until they die.

Nevertheless, 60 percent of Americans die in acute care hospitals, and another 20 percent die in nursing homes.[4] Why should that be?

In 2014, the Institute of Medicine published the committee report *Dying in America — Improving Quality and Honoring Individual Preferences Near the End of Life*.[5] The Institute, now called the National Academy of Medicine, also sponsored a daylong seminar to consider the recommendations of the report. They discussed ways of improving end-of-life care, including discussions with various stakeholders, improvements in public and private payment systems as well as recognizing the importance of integrating health and social services to optimize patient quality of life and care.

Gawande delivered the keynote address, and among his crucial points were these:

- Through the medicalization of mortality, we can actually increase suffering
- There is more to well-being and living well than survival
- It is key to know the patient's definition of a good life or an acceptable life. To this end, doctors must recognize the patient's demand to have a life worth living;
- We must optimize goal-directed care over disease-directed care.

Drawing upon these points, as well as on the Institute of Medicine's report, a physician who facilitates the appropriate conversations can lead a patient and family to a care plan associated with less suffering, less family or caregiver fatigue, less time in the intensive care unit extending death rather than life, less in health care costs, less misunderstanding, and a possible survival advantage shown in at least two separate studies involving hospice or palliative care.

By seizing the opportunity to choose one's options — whether they be heroics that include mechanical ventilation, dialysis, cardiopulmonary resuscitation, feeding tubes, prolonged or repeated hospitalizations, as well as living in a nursing home, or the alternative of continued medical care with an emphasis on comfort through palliative care, the patient remains in control and is the decision-maker. Standing at the ready is hospice to optimize comfort when cure is no longer a likelihood.

These discussions are important to your patients, their families and you. They are best held while options are available to protect patient choice, patient care and patient dignity as he or she confronts end-of-life issues.

We will not convince those who do not want to be convinced that hospice is a reasonable, beneficial activity.

A MATTER OF TRUST

In my role as Critical Healthcare Decisions consultant, I am called upon to have "the conversation." I look forward to these personal interactions, and I draw on all my medical experience and ethics training.

I have found that sometimes people feel like they know what they want, but they aren't sure they can give themselves "permission." To me, it seems reasonable to tell a patient or family that it is permissible to choose what they feel is best for them — which includes allowing nature to take its course. They do not have a duty to adhere to a principle of vitalism in which life, of any or no quality, is imperative. What is imperative is that patients consider the choices and alternatives themselves.

Part of the Critical Healthcare Decisions physician's job is to solidify trust. Edmund G. Howe, MD, JD, has written elegantly regarding the importance of gaining and maintaining trust.[6] He provides several useful tenets, among them: don't impose moral views unnecessarily; do know the limits of ethical expertise; do not engage in flawed moral reasoning or rationalization; support patient decision-making; give over as much control as possible to the patient; and try to clarify any ambiguities to avoid confusion.

In order to participate in "the conversation," we physicians should recognize evolving medical issues in determining true prognosis of the chronically ill, the chronically critically ill and the critically ill patient in the intensive care unit. We should understand issues concerning age and patient frailty and the relationship between the two. A clear understanding of the prognosis for patients with advanced dementia is appropriate. Newer ethical arguments should be considered, such as regarding cardiopulmonary resuscitation in the context of balancing benefit versus harm rather than as the default action, as described in a 2017 article in the *Journal of Clinical Ethics*.[7]

Greater public emphasis on palliative care will provide comfort to those concerned about abandonment and help to provide a true continuum of care. This premise has been underscored by Pope Francis, who called palliative care "an expression of the properly human attitude of taking care of one another, especially those who suffer."[8]

Still, there are people who don't see palliative care that way. For example, patient RH has been under my care for 20 years, as was his recently deceased wife. Their daughter Cindy has been my patient for almost 30 years.

RH is more than 90 years old and is not quite in full control of his faculties. He is intermittently confused and as angry as a grizzled World War II bomber pilot can be. He falls frequently. He has venous insufficiency and recently developed a popliteal vein thrombosis.

On several occasions, he has declared he was not interested in heroic care and preferred a DNR status. He certainly wants to stay home for his remaining time. Cindy initiated hospice care to optimize his comfort.

Enter, from out of state, his other two daughters and his son-in-law Lou. They all were convinced that hospice care meant abandoning RH to death, but that RH really wanted to live. Lou endeared himself to the hospice team by stating, "Hospice is a cult."

We will not convince those who do not want to be convinced that hospice is a reasonable, beneficial activity. Perhaps, though, we need to do a better job not only of understanding the patient's wishes, but of communicating and discussing them with concerned family members so that they can accept, as Gawande writes, that "the patient would certainly like to live, but at this stage finds the avoidance of suffering, relationships with family and friends, being aware, not being a burden on others and achieving a sense of a complete life to be equally or more important."[9]

CONCLUSION

Physicians have an active role to play in guiding patients, their families and loved ones through the most important of personal health care decision-making. To do our patients justice, we must draw on our in-depth understanding of the practice of medicine, including critical care as well as the tools of frailty assessment and illness prognostication. We must develop an understanding of basic medical ethics, including the concepts of patient dignity and autonomy. Finally, we must prepare ourselves for guiding "the conversation" to a conclusion most acceptable to the patient.

With that in mind, my "retooling" approach could make it possible for many experienced physicians like me to take one more extended walk.

ANTHONY M. COSTRINI is a pulmonary disease physician, intensivist and sleep medicine specialist as well as quasi-medical ethicist and palliative care enthusiast in Savannah, Georgia. He prides himself on his family, his citrus trees and his world-famous limoncello.

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NOTES

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