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# Initiating End-of-Life Discussions With Seriously Ill Patients

## Addressing the “Elephant in the Room”

Timothy E. Quill, MD

**P**ERSPECTIVES ON CARE AT THE CLOSE OF LIFE IS A SERIES of case-based discussions that present challenging problems in caring for patients with end-stage, serious illness—those near or at the end of life. The series incorporates segments of actual interviews with patients, their family members, and their primary care physicians, each of whom consented to share their perspective. What follows is an evidence-based discussion of typical issues illustrated by the patient's story.

### THE PATIENT'S STORY

Mr B is an 81-year-old father of 6 with advanced pulmonary fibrosis, type 2 diabetes mellitus, atrial fibrillation complicated by a stroke, and chronic renal insufficiency. A retired shipbuilder and construction worker, he enjoys sailing and photography.

Two years ago, prior to being interviewed, he developed cor pulmonale. He was hospitalized 4 times last year and made multiple emergency department visits. He lived at home with his children until his most recent hospitalization, after which he was admitted to a nursing home because of intractable weakness, shortness of breath, and dependence on others to perform his activities of daily living. He has completed a do-not-resuscitate document and stopped taking anticoagulants and immunosuppressants.

### PERSPECTIVES

Mr B and his son were interviewed by the author on February 3, 2000, during a medical grand rounds devoted to discussing palliative care at the University of California, San Francisco's Moffitt-Long Hospitals. Dr G, Mr B's primary care physician, was interviewed by one of the section editors later that month.

**MR B:** *I've had a good life. I think when the time comes I'm ready. I don't want extended medical treatment or a breathing machine. My wife died very young of an incurable brain tumor. She begged people to smother her with a pillow or something. She became gradually worse until finally about the only thing she could move was her eyes. We nursed her along from when she became immobile until she finally passed away. It was a long, drawn-out affair for the children, so I think they've had plenty of experience.*

**For editorial comment see p 2512.**

Discussions about end-of-life issues are difficult for clinicians to initiate. Patients, their families, and clinicians frequently collude to avoid mentioning death or dying, even when the patient's suffering is severe and prognosis is poor. In addition to determining from observational research when and where communication problems exist, much can be learned from in-depth discussions with patients, family members, and physicians who are facing these issues together. Using segments of interviews with a patient with advanced pulmonary fibrosis, his son, and his primary care physician, this article illustrates and explores some of these communication issues, including the who, what, when, why, and how of end-of-life discussions. Studies from the medical literature, the patient's and physician's particular experience together, and the author's clinical experience provide practical insights into how to address these issues. Initiating end-of-life discussions earlier and more systematically could allow patients to make more informed choices, achieve better palliation of symptoms, and have more opportunity to work on issues of life closure.

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*ience. I wasn't holding her hand when she died, and I've never forgiven myself. Hindsight . . . If you really knew what was coming. But it's a mystery, huh? There are always thousands of things that you need to take care of now. Oh, well everybody does that, don't they? Don't they look back and say, "If I'd only . . . ?"*

*I have a very good doctor. She's told me herself I can count on her. That made me feel very good. I've gotten over the scary part. There are times in your life when you know it's going to end, and you just have to make up your mind about it ahead of time.*

**DR G:** *I think about it in relative terms, where he is now compared to when I met him over 3 years ago. His quality of life and ability to function are much less. His spirits seem more subdued and he seems quite impaired by his illness. He never really mentions the word death, or says "I'm dying," but he says things in very simple terms, such as "If I get worse, I'm just going to get worse."*

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He says he's willing to accept it. Without naming the end point, we're clearly saying he's getting sicker. The next step was "Let's talk about what you would want to do if you got worse, couldn't breathe, came to the hospital." He said, "I don't want anything." I asked him if he knew what that meant. I explained that if he came in, we would make him comfortable. It might mean fluids and things like that, but we wouldn't put him on the ventilator, or give medications that he didn't want. He wouldn't suffer.

It's hard personally because I really like him. He has an independent spirit . . . a lot of clinic visits are spent talking about different things he's doing and thinking about. I'm going to be very sad when he dies. When I think about my practice I'll miss seeing him there. That face.

MR B'S SON: Even though he has breathing problems and heart problems, he is at least capable of getting around in his wheelchair. I'd like to see him keep going and do some things, and he would like that. We're all aware that at some point it's going to end, but want to keep going until it happens.

### THE DOCTOR AND PATIENT: FACING THE INEVITABLE TOGETHER

MR B: Death is a very scary word, but we all have to do it some way or the other. So when we get ready to do it, let's do it.

DR G: . . . it was always hanging over my head . . . it was the unacknowledged elephant in the room. Every day I worried that he'd come in with pneumonia by ambulance in the middle of the night and I wouldn't hear until the morning that he'd been intubated. I knew I'd feel terrible. I knew this was not what he wanted so I needed to get it settled.

Patients like Mr B are living longer, partly due to medical successes of the past 40 years. The intent of medical advances was that health would be maintained a lot longer, morbidity would be compressed, and death would come peacefully.<sup>1</sup> Although on average US residents are healthy slightly longer, they spend much more time in dependent states of progressive debility.<sup>2,3</sup> Nearly 80% of US residents die in hospitals or long-term care facilities.<sup>4</sup> At the time of death, three quarters are nonambulatory, one third are incontinent, and 40% are cognitively impaired.<sup>5</sup> The end of the dying process is often filled with clinically challenging, ethically complex decisions about withholding or withdrawing potentially life-prolonging treatment.<sup>3</sup> Death has frequently become dominated by difficult medical choices, associated with existential, spiritual, and moral confusion, rather than being simply a natural end to the lifecycle.<sup>6</sup>

With death imminent, patients worry that no one is listening and fear dying with unnecessary pain and suffering.<sup>7</sup> The SUPPORT study, a multicenter trial enrolling more than 9000 seriously ill patients, suggests that these fears may be warranted.<sup>8</sup> That study found that 50% of the patients who remained conscious at the end of life experienced moderate to severe pain at least half the time in their final 3 days of life, 46% of do-not-resuscitate (DNR) orders were written 2 days before death, and only 47% of physicians knew patients' DNR preferences.<sup>8</sup>

Timely, sensitive discussions with seriously ill patients regarding medical, psychosocial, and spiritual needs at the end of life are both an obligation of and privilege for every physician.<sup>9</sup> These discussions clarify treatment options and may shift the emphasis from cure to palliation.<sup>10</sup> Palliative care focuses primarily on relieving pain and physical symptoms, enhancing psychosocial supports, and allowing patients and families to achieve meaningful closure.<sup>11,12</sup> These opportunities should be offered to all seriously ill patients, regardless of their views about continuing disease-directed interventions. As the extent of suffering progresses out of proportion to prognosis, some patients choose palliation as their primary objective. Unfortunately, palliative care is frequently offered late in the dying process, if at all, and as an alternative to usual medical care as opposed to something that can enhance or supplement it.<sup>4,13,14</sup> Hospice, a system for providing palliative care, is underused even for patients with advanced cancer.<sup>4</sup> The barriers imposed by policy requirements (eg, highly likely to die within 6 months; willingness to forgo expensive disease-directed treatments) further conspire against hospice selection.

Physicians are also reluctant or unable to tell patients that they are likely to be approaching the end of their lives.<sup>15</sup> When physicians do talk about prognosis, they tend to be overly optimistic.<sup>16</sup> This inability to relay unfavorable prognostic information results both from medicine's inherent prognostic uncertainty<sup>17</sup> and from clinicians' fears that they will be perceived as "giving up" if they talk about dying, thereby eliminating hope and depressing patients. However, studies have found that not only is this not necessarily the case,<sup>18</sup> but failure to provide appropriate information about palliative care and prognosis can contribute to unnecessary pain and suffering.<sup>8</sup>

### WHEN SHOULD END-OF-LIFE DISCUSSIONS BE INITIATED?

DR G: We had a series of hospital admissions and many clinic visits for scary episodes—shortness of breath, passing out, falling out of his wheelchair . . .

MR B: Why do all these stretching out of life measures? It's not an easy thing, but . . . it's inevitable, so you just have to prepare yourself for it.

MR B'S SON: He's been ill for some time. It seems fairly imminent. I think most of the family is prepared for it. He's been rushed to emergency on many occasions over the last couple of years. Like my dad says, it's inevitable, and we're pretty much fatalistic about it.

Consensus has evolved among clinicians that meaningful end-of-life options are usually offered too late. Fewer physicians agree as to the clinical markers signaling the time to initiate discussions (TABLE 1). The following situations suggest urgent indications:

- **Patients facing imminent death.** When death appears imminent, immediate discussion is essential. Frequently death has been predictably approaching for some time and discussion already has been delayed too long.<sup>14</sup>

**Table 1.** Clinical Indications for Discussing End-of-Life Care

Urgent Indications
Imminent death
Talk about wanting to die
Inquiries about hospice or palliative care
Recently hospitalized for severe progressive illness
Severe suffering and poor prognosis
Routine Indications
Discussing prognosis
Discussing treatment with low probability of success
Discussing hopes and fears
Physician would not be surprised if the patient died in 6-12 months

• **Patients who talk about wanting to die.**<sup>19</sup> Sometimes inquiries about assisted dying are really requests to shift from restorative to palliative treatment, particularly if the patient has uncontrolled pain, a family or spiritual crisis, or serious depression.<sup>20</sup>

• **Patients or families inquire about hospice.** Hospice questions may be a subtext for exploring specific fears about the future, or a sign that a patient wants to reconsider the goals of treatment or address unrecognized suffering.

• **Patients recently hospitalized for severe progressive illness.** Hospitalizations, particularly when repeated, suggest that death may be approaching and can prompt a discussion of prognosis and preparing for the end.

• **Patients suffering out of proportion to prognosis.** When clinicians feel uncomfortable approaching or treating a patient because of clearly evident suffering, end-of-life issues may have been ignored. Seventy percent of medical residents report that they go against their consciences in treating hospitalized patients overly aggressively while under-treating pain and symptoms.<sup>8,21</sup>

Routine discussions about end-of-life issues may serve all seriously ill patients, even those with a reasonable chance of stabilization or recovery. Normalizing the discussion allows patients to learn about their right to high-quality pain and symptom management<sup>22</sup> and educates clinicians about patients' values and goals. Asking "What would be left undone if you were to die sooner rather than later?" gives a message that time may be short.<sup>23</sup> The indications for routine discussions might be:

• **When discussing prognosis.** Although frequently avoided or glossed over to "protect" patients and their families,<sup>15,16</sup> realistic discussions about prognosis may reassure patients and families wondering what will happen if treatment does not go as hoped.<sup>24,25</sup>

• **When discussing treatment options with a low probability of success.** Some patients choose to continue therapy with considerable toxicity and poor odds of success simply because they have been presented with no meaningful alternatives that emphasize enhancing quality of life.

• **When discussing hopes and fears.** Most severely ill patients and families hope for the best and imagine the worst. Pledging to provide meaningful choices and comprehensive palliative care in the future can allay many fears.

• "Would I (the clinician) be surprised if the patient died within the next 6-12 months?"<sup>13</sup> Prognosticating as to when a particular patient will die is inherently inexact. Waiting to discuss end-of-life issues only with those patients highly likely to die restricts the conversation to patients with a few diseases carrying a predictable terminal trajectory.

Mr B met several of the "urgent indications." He articulated fear of future suffering and talked about wanting to die. His physician felt uncomfortable continuing invasive treatment given his current burden of suffering and poor prognosis, yet initially avoided discussions about future cardiopulmonary resuscitation (CPR). No one involved in his care would be surprised if Mr B were to die within 6 months. As we learned, Mr B's physician and his family were more reluctant to start the discussions than he was.<sup>24</sup>

### WHO WILL INITIATE AND SUSTAIN DISCUSSION ABOUT END-OF-LIFE ISSUES?

DR G: *I knew he was ready . . . and had planned a home visit. The first time we tried, at his daughter's home, it was really difficult, partly due to the setting. Maybe next time I'll schedule a separate time to meet privately in clinic, to have this conversation and not deal with medical issues.*

Because of their long-standing, committed relationship, Dr G was in an ideal position to initiate and sustain discussions about care at the end of life, yet she had difficulty finding a comfortable venue. Some patients, like Mr B, have clearly articulated wishes and values, but even they typically rely on their physicians to initiate the discussion.<sup>25</sup> After making a DNR decision together, Dr G was prepared to shepherd Mr B through the many clinical and ethical challenges that characterize the last phase of his life.<sup>26</sup>

All too frequently, patients and families do not have a long-term relationship with a physician, or if they do, this relationship is threatened, especially when patients change health care settings or programs toward the end of life.<sup>4</sup>

DR G: *[Now] I've sort of lost him in the system. He's going to get placed [in a skilled nursing facility] eventually and be taken away from me. That's not how I imagined the ending. . . . [I'd hoped] he'd be at home with his kids and we would be doing this through home hospice . . . where I could be a big part of it.*

Unfortunately, but not atypically, this patient-physician relationship is threatened by Mr B's admission to a nursing home where medical care is managed primarily by institutionally based physicians. Physicians' roles are becoming increasingly fragmented over the continuum of care—outpatient care by primary care physicians, inpatient care by hospitalists, and nursing home care by geriatricians. Physicians like Dr G with long-standing patient relationships are in the ideal position to make palliative care decisions with patients and families.<sup>27</sup> Every effort should be made to involve them in major medical decisions across all settings.<sup>28</sup>

In the absence of such a relationship, a single physician should be designated to coordinate and communicate the medical aspects of each patient's overall care throughout his/

her stay in a given facility, including disease-related and palliative care issues. This physician should encourage full participation by the entire team, including nurses, social workers, pharmacists, clergy, and family members, as desired by the patient, to maximize the development of a trusting context for subsequent decision making. Patients and families should be able to answer the question: “Who is your main doctor?”

### WHY INITIATE END-OF-LIFE DISCUSSIONS?

INTERVIEWER: . . . [Y]ou have this opportunity now to think about, and potentially do, some of the things that you might say are really important.

MR B: Yeah, but you never get them done. I would like to write some poetry, but I just can't bring myself to start it.

MR B'S SON: We're a great family of procrastinators. That's why he's still here, he's procrastinating.

Many patients need to know about their clinical conditions and prognoses because their choices differ based on this information. Clinicians are obligated to inquire about patients' values and wishes, and fully inform them of the likelihood of success of aggressive interventions. A case in point is CPR, a harsh procedure usually incompatible with a peaceful death. Discussing DNR is often the first time that patients and families contemplate death and the limitations of aggressive medical measures. Ironically, in the absence of clear information, patients often agonize over CPR, despite abundant evidence that almost no patients with multiple, severe, chronic illnesses who receive CPR survive to discharge.<sup>29-31</sup> Patients are less likely to choose CPR once they learn of its lack of efficacy.<sup>29,30,32</sup> Beyond addressing CPR, palliative care discussions present the opportunity to confront uncomfortable or unrecognized symptoms, such as pain, nausea, and dyspnea.

Mr B clearly did not want CPR (“Artificial means of keeping me alive—I don't want any of that. Let me get it over with”). Had his physician procrastinated or avoided these discussions, the default approach during an unexpected arrest, or on presentation to the hospital in extremis, would have been full resuscitation, against the patient's wishes. Apart from medical implications, avoiding end-of-life discussions also may deprive patients of the opportunity to work on issues of life closure. Tasks such as writing poetry, healing family relationships, or completing a will may be left unattended if the patient is unaware that death may be approaching.

### WHAT SHOULD BE INCLUDED IN END-OF-LIFE DISCUSSIONS?

DR G: [discussing treatment] Should we take a more aggressive approach? Does he need steroids? Does he need immunosuppressants for pulmonary fibrosis? We toyed with that for 2 months. Then he decided that he actually didn't want any of it. He and I were just going to work together. If this was going downward, we were going to let it.

MR B: It's going to end up that I can't breathe . . . they've explained that there's so much damage to my lungs there's no way that they can fix them. They'll just get worse. . . . I've gotten over

**Table 2.** What to Include in Most End-of-Life Discussions

General: Goals of Treatment	
Relative emphasis on life prolongation	
Relative emphasis on quality of life	
Specific: Range of Intervention	
Advance directives	
Living will	
Health care proxy	
Do not (attempt) resuscitation (DNR) orders	
Other life-sustaining therapies, such as:	
Mechanical ventilation	
Feeding tube	
Antibiotics	
Hemodialysis	
Palliative care	
Management of pain and other symptoms	
Relief of psychological, social, spiritual, and existential suffering	
Creating opportunity to address unfinished business	

the scary part. I was emphatic about the way I wanted to be treated. And if I got turned loose among a bunch of doctors, who knows what would happen?

A discussion of the relative weight placed by the patient on prolonging life as opposed to enhancing quality of life should usually precede considerations of particular treatment choices (TABLE 2). Mr B clearly values enhancing his quality of life, avoiding overtreatment, and maintaining personal control, thereby providing a clear context for subsequent discussion about the range of specific interventions.

Although goals should be explored with all seriously ill patients, not every treatment option must be discussed with every patient. Events considered likely to occur given the clinical condition (such as mechanical ventilation for Mr B) must be discussed. In the absence of clear directives, in an emergency, patients receive all available life-prolonging technology. Since Mr B was adamant about not wanting CPR, he needed the Medi-alert bracelet and home DNR order that resulted from this discussion so that emergency medical technicians would refrain from initiating CPR. Furthermore, since Mr B did not want to be kept alive if he lost mental capacity to speak for himself, he legally designated one of his children as health care proxy and stated his desire for “comfort measures only” under these circumstances.

Because Mr B had made numerous emergency department visits for severe shortness of breath, he knew what his future might hold. Yet a decision against intubation and resuscitation must also address management of symptoms, such as acute dyspnea, that are likely to be confronted in an emergency situation. In Mr B's case, this situation may include a trial of intravenous diuretics and corticosteroids, but also the promise of gradually escalating doses of morphine if he continued to struggle with severe dyspnea.<sup>31</sup>

### HOW SHOULD END-OF-LIFE DISCUSSIONS BE BROACHED?

INTERVIEWER: A lot of people worry about doctors talking you into things. Did you want her to try to tell you what she thought about [DNR]?

MR B: *Sure.*

DR G: *When we first talked about it, I talked more in terms of options: "We can be very aggressive or we can do what we're doing now," but we didn't name the third one, which is "We can do even less." That came next. It sort of came in steps. The first step was deciding not to be aggressive with a lot of medi-*

*cations, hospital admissions, and procedures. That was the first decision, and that was his.*

Although there is no simple formula for initiating end-of-life discussions, TABLE 3 illustrates some representative questions for initiating discussion in a variety of domains. The physician should keep questions straightforward, listen carefully to answers, and then follow the patient's lead by asking focused follow-up questions incorporating the patient's language when possible. For example:

**Physician:** "What has your life been like outside of the hospital?"

**Patient:** "It has been very hard on all of us."

**Physician:** "What is the hardest part for you and your family?"

**Patient:** "My children are very good, but this has turned our family life upside down."

**Physician:** "Tell me more about that?"

After fully exploring the concerns of the patient and family, the physician should eventually conduct a "values history" by asking questions such as "What makes life most worth living?" and "What circumstances would make it not worth living?"<sup>37</sup> Usually these general explorations of values, goals, and expectations precede discussions about particular methods of treatment.

DR G: *I was worried that [our DNR discussion] would get back to his kids. I felt in some ways I was buffering him a little bit from his kids. I wasn't sure how they were going to react.*

MR B's SON: *I'd like him to hang around for a while because I enjoy him very much. I would hate to lose the guy.*

Mr B clearly has full capacity to be the central decision maker for his life, yet his family is very invested in his continued longevity. The physician must ultimately guide the discussion to the most critical medical aspects of the decision,<sup>38</sup> but can also serve as the patient's mediator and advocate with the family.<sup>34,39,40</sup> In these discussions a keen awareness of the patient's cultural, ethnic, and religious background is critical, as these contextual issues may profoundly influence decisions.<sup>41,42</sup> ("I was baptized a Catholic but I never followed up on it. I think that when a person reaches a certain point, if they want to die, they should. . . . I don't think a superior being is telling us how we have to go.")

Throughout the late stages of disease, physicians are frequently called on to address difficult questions (TABLE 4). Existential and spiritual questions may not be answerable, but all questions call for an honest and compassionate response.<sup>7,23</sup> Questions about prognosis may be answered as a range of time periods (eg, "minutes to hours," or "days to weeks," or "months to years") while always acknowledging the possibility of exceptions in either direction, and the potential frustration of not being able to prognosticate more precisely. Physicians should not shy away from making recommendations or providing guidance, particularly when requested by the patient or family.<sup>38</sup> With her intimate knowledge of his medical condition and his personal wishes, Mr B's physician recommended completing a DNR document. Although mak-

**Table 3.** Representative Questions for Initiating the Discussion About End-of-Life Issues\*

Domain	Representative Questions*
Goals <sup>33</sup>	Given the severity of your illness, what is most important for you to achieve? How do you think about balancing quality of life with length of life in terms of your treatment? What are your most important hopes? What are your biggest fears?
Values <sup>37</sup>	What makes life most worth living for you? Would there be any circumstances under which you would find life not worth living? What do you consider your quality of life to be like now? Have you seen or been with someone who had a particularly good death or particularly difficult death?
Advance directives <sup>34, 35</sup>	If with future progression of your illness you are not able to speak for yourself, who would be best able to represent your views and values? (health care proxy) Have you given any thought to what kinds of treatment you would want (and not want) if you become unable to speak for yourself in the future? (living will)
Do-not-resuscitate order <sup>36</sup>	If you were to die suddenly, that is, you stopped breathing or your heart stopped, we could try to revive you by using cardiopulmonary resuscitation (CPR). Are you familiar with CPR? Have you given thought as to whether you would want it? Given the severity of your illness, CPR would in all likelihood be ineffective. I would recommend that you choose not to have it, but that we continue all potentially effective treatments. What do you think?
Palliative care (pain and other symptoms) <sup>23</sup>	Have you ever heard of hospice (palliative care)? What has been your experience with it? Tell me about your pain. Can you rate it on a 10-point scale? What is your breathing like when you feel at your best? How about when you are having trouble?
Palliative care ("unfinished business") <sup>10</sup>	If you were to die sooner rather than later, what would be left undone? How is your family handling your illness? What are their reactions? Has religion been an important part of your life? Are there any spiritual issues you are concerned about at this point?

\*Physicians should give the patient an opportunity to respond to each question. Base follow-up questions and responses on careful listening to the patient, using his/her own words whenever possible.

**Table 4.** Some Difficult Questions From Patients

"Why me?"
"Why didn't you catch this earlier? Did you make a mistake?"
"How long do I have?"
"What would you do in my shoes?"
"Should I try long-shot or experimental therapy?"
"Should I go to a 'medical mecca' for treatment or a second opinion?"
"If my suffering gets really bad, will you help me die?"
"Will you work with me all the way through to my death, no matter what?"

ing this recommendation caused her anxiety, withholding her experience and guidance would have been inhumane.

### WHY DO WE DO WHAT WE DO?

DR G: *Talking about it with him was very hard because I knew him very, very well . . . and was so invested in him. I had my opinion about what his code status should be and how much treatment he should have. I hoped I was giving him good advice. . . . I remember saying something like, "If it helps, I agree with your decision." I was thinking it might help him to know somebody was with him.*

Dr G struggled with her feelings, but ultimately chose to share her views about resuscitation with Mr B. This was both a statement of solidarity with Mr B and a willingness to help him make the best decision possible. Because she cared deeply about Mr B, what happened to him in the last phase of life mattered to her personally.<sup>27</sup> Engaging in intimate, end-of-life decision making with patients and families can be both emotionally enriching and psychologically draining. Physicians should share uncertainties about treatment options and solicit input from other members of the health care team. Equally critical for clinicians involved in end-of-life care is the opportunity to discuss personal reactions and receive support in a safe place.<sup>43</sup>

Helping patients achieve as good and meaningful a death as possible is part of what we do as physicians. When physicians provide their patients with the honesty, expertise, advocacy, compassion, and commitment they would want for themselves and their families, they provide the highest quality of medical care possible. For some patients, the approach will include an improbable fight for life at the cost of considerable iatrogenic suffering. For others, the primary goal will be to enhance quality rather than length of life. Some, like Mr B, will be open and articulate about their end-of-life wishes and values, whereas others may not want much open discussion. Allowing for these differences, patients must receive excellent pain and symptom management, clear information and guidance about their disease-related and palliative care treatment options, psychosocial support, and, if desired, an opportunity to work on life closure. There is little or nothing to lose in initiating palliative care discussions earlier and more systematically in a patient's final trajectory, and so much is lost when these discussions are avoided.

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