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The Need for Uncertainty:

a case for prognostic silence

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Abstract

Disclosure of prognosis in end-of-life care is a practice that is widely and increasingly recommended. However, prognostic disclosure is known to be resisted by many dying persons and by physicians, who instead engage in a “collusion of silence”—discussing prognosis either not at all or in vague, indirect terms. Debates about the ethics of prognostic disclosure and non-disclosure have tended to focus on their relative benefits and harms, or on the psychological acceptability of prognostic information to dying persons. Unaddressed, however, is a more fundamental assumption upon which the practice of prognostic disclosure depends: that prognostic certainty is what dying persons ultimately need. In this essay I question this assumption. Reflecting on the experience of my father’s recent death, I argue that prognostic certainty is not only unattainable but existentially irrelevant to many dying persons, and that prognostic uncertainty can be a greater need. Respect for individuals’ existential need for uncertainty justifies prognostic silence and enables dying persons—as well as the loved ones and clinicians who care for them—to be open to new possibilities of finding meaning at the end of life.

No fact in human nature is more characteristic than its willingness to live on a chance. The existence of the chance makes the difference between a life of which the keynote is resignation and a life of which the keynote is hope.

—William James (1902)

Powerful forces are promoting the ideal of prognostic disclosure in end-of-life care. Advances in the science of prognostication—ranging from increasingly accurate clinical prediction models to new genomic risk factors—are expanding the supply of prognostic information. Meanwhile, the growing palliative medicine and shared decision-making movements are heightening the demand to disclose prognosis to seriously ill patients. Prognostic disclosure is thought to be beneficial in facilitating advance care planning and informed patient choice, while diminishing unrealistic patient expectations and demands for ineffective treatments.

Nevertheless, prognostic disclosure is not yet the norm in end-of-life care. Instead, physicians and advanced cancer patients often engage in what has been termed a “collusion of silence”—discussing prognosis either not at all or only in imprecise, indirect, or inexplicit terms (The et al. 2000). It is tempting, given the many forces promoting prognostic disclosure, to dismiss this collusion as irrational and unethical. As oncologist Paul Helft (2006) has argued, however, the situation is more complicated: prognostic non-disclosure is consistent with some patients’ wishes, preserves hope by acknowledging uncertainty, and

helps patients digest difficult information over time. These factors, he claims, justify a “necessary collusion”: a “style of communication that allows patients to dictate most of the flow of prognostic information or to avoid it” (3146).

Like many physicians, I have struggled with this issue; however, I find these arguments convincing. They are consistent with both my professional experience as a palliative care physician and researcher who has worked to improve the estimation and communication of prognosis and uncertainty, and my personal experience as a human being who has had the inevitable misfortune of witnessing the deaths of a growing number of patients and loved ones, including my mother and, most recently, my father. These cumulative experiences have taught me that prognostic nondisclosure is not necessarily harmful—and may indeed be beneficial—for many dying persons.

But I would go even further. At the crux of contemporary efforts to promote prognostic disclosure lies a fundamental assumption: that prognostic certainty is what dying persons really need. I believe this assumption is fundamentally mistaken, and in this essay I will defend this claim. Reflecting on the experience of my father’s recent death, I argue that prognostic *uncertainty*—rather than certainty—is a greater, existential need for at least some dying persons, and that this need justifies prognostic silence. I do not claim that such silence is always justified, only that the need for uncertainty can sometimes make prognostic information irrelevant. The need for uncertainty, furthermore, extends not only to dying persons but to those of us who care for them. What our approach to prognostic disclosure ultimately requires, I believe, is flexibility and openness, driven by a humble acknowledgment of limits in our capacity to know what is right.

A Collusion of Silence

My father’s liver cancer was a long time coming and not unexpected from a medical standpoint. Maternal-fetal transmission of the hepatitis B virus 81 years ago, a common occurrence in Korean villages like my father’s birthplace, began the process, followed by longstanding chronic infection. The final causal link in the chain: malignant transformation leading to multifocal hepatocellular carcinoma, uncovered by a screening ultrasound.

Yet many aspects of my father’s life and illness were truly exceptional. He endured and survived numerous hardships and uncertainties throughout his entire life, including the upheavals of foreign occupation and war as a child in Korea; emigration to the United States as a young man; a pioneering career as an Asian Protestant clergyman in various small towns in Ohio; the incalculable challenges of raising a family in an adopted land. Due to a unique admixture of deep religious faith, dispositional optimism, and aversion to medical attention (despite the fact that his two sons became physicians), my father lived most of his life unaware of his hepatitis. When it was finally diagnosed 30 years ago, he already had early cirrhosis. He underwent evaluation for liver transplantation 20 years ago, which he declined to pursue, when he was also diagnosed with an idiopathic myelodysplastic syndrome manifested by severe thrombocytopenia. At the time I doubt that any physician anywhere would have predicted my father would live for 20 more years with his cirrhosis, dangerously low platelet count (<10K), and no complications other than an idiopathic

pleural effusion that mysteriously appeared four years ago, was treated by chest tube drainage, and just as mysteriously disappeared without recurrence.

For all I knew about my father and his medical conditions, there was just as much that remained unknown. How he lived his life—as a trusting, passive recipient of minimal medical attention, oblivious to his prognosis while soundly beating the odds—was a mystery. All I knew was that his faith-based approach paradoxically arose from a deep uncertainty—a heightened consciousness of human ignorance. Over the years my father delivered many sermons citing the words of St. Paul: “For now we see through a glass, darkly” He affirmed his belief in a “fourth dimension” of reality beyond space and time, perception and comprehension. Consciousness of the limits of understanding undergirded his non-deliberative, opportunistic approach to life: when a door opens, even if all that lies on the other side is the sheer unknown, you walk through it with faith, courage, and optimism. “Let go, let God” was my father’s oft-stated credo that carried him through many doors over the years.

My father applied this approach to the most life-altering choices; a prime example was his non-premeditated decision to come to the United States, prompted by a classmate waving a plane ticket in his hand. Yet passive non-deliberation also characterized my father’s approach to far less momentous tasks, which could test the patience and humor of anyone unable to share his childlike faith that things would always work out. My own faith was tested on a family journey several years ago to visit long-lost relatives in the unfamiliar Korean countryside, when I belatedly discovered—only after traveling by bus to a town somewhere in the general vicinity—that my father had neither contacted his relatives, researched their location, nor planned in advance how to get there or where we would stay. To my grateful disbelief, a random child on a roadside eventually pointed us in the right direction.

Somehow a door always seemed to open for my father, and his faith would carry him successfully through. His life was a miraculous story of unwitting survival, a continually branching stream of improbable coincidences and conjunctions, medical and non-medical. Still, I always sensed my father was living on borrowed time. So when I received news of his cancer, I wasn’t surprised. Yet I also could not help wondering whether this diagnosis, too, would prove to be just another prognostically inadequate category, and my father’s faith would simply carry him through once again.

As it turned out, only the latter was true. My father’s oncologist recommended trans-arterial radioembolization (TARE), stating—to my brother only—that the prognosis for patients like my father was “usually less than one year,” but “with treatment we can often buy an extra one to two years.” No one conveyed these estimates to my father, but it did not matter; to him there was no choice other than treatment. As with every challenge he faced, his approach was to “go with the flow.”

Unfortunately, the treatment did not work. Over the next several weeks my father became increasingly weak, fatigued, and anorexic. He required increasing support that my brother, our relatives, and I provided in several-day shifts. His functional status declined inexorably,

starting with walking and eating, followed by transferring and then toileting. He refused a second planned TARE, which would have been out of the question anyway given his functional decline. Home hospice care was eventually initiated, and my father moved in with my brother. Soon afterwards his condition deteriorated acutely, likely due to an aspiration pneumonia, and he died about two weeks later—roughly four months following his cancer diagnosis.

Throughout this time the tensions and ironies of prognostic silence loomed large. Shortly after the TARE, and on the very weekend I gave a presentation on barriers to prognostic communication in end-of-life care at a national research conference, I visited my father and steadfastly avoided any discussion of prognosis. I struggled with my ambiguous position: as a physician I felt compelled to discuss his prognosis openly, while as a son I was all too happy to remain silent. In the end I played the part of a son—passively watching, tacitly reinforcing my father's worldview through my silence. Meanwhile, he pushed ahead through profound weakness with equally profound determination, forcing himself to eat and ambulate. There was no question that he hoped for a cure. For weeks he resisted telling even his closest relatives he had cancer; he called this his “cry of faith.” Even in his final days he talked about attending events in the coming year, once he got better. Seeing my father emaciated and weak, single-mindedly struggling to move forward with small, shaky steps—ever hopeful while not knowing what lay ahead—I imagined how he might have looked and felt as a child during the Japanese occupation and Korean War, when his family was displaced and forced to journey great distances by foot. But I knew that this time I was simply bearing witness, in slow motion, to my father's death.

My brother and I—who had spent our more privileged lives dealing in different, sometimes conflicting ways with the various uncertainties posed by my father's life and illness—privately worried about the impact of prognostic silence on our ability to say goodbye and put his affairs in order. We missed this chance with our mother, who had died suddenly 10 years ago. But these worries proved more important to us than to my father. We gently encouraged him to “hope for the best and prepare for the worst,” but discovered how unhelpful this rubric is when the worst, from his perspective, was simply out of the question: “Let's just see what happens” was his enduring response. In the end, preparation for the worst had to occur without him, and as it approached my family seized every opportunity to share our love and say our goodbyes. Yet my lingering fear was that this last door would close before I could really let my father know how much I loved him.

Necessity and Possibility: The Need for Uncertainty

Conventional medical wisdom attributes avoidance of prognostic information to a variety of psychological factors and constructs: denial, death anxiety, unrealistic optimism, among others. In this narrative, prognostic silence represents an “irrational” defense mechanism that somehow needs to be overcome. Patients like my father simply “don't get it” and require education and decision support. Clinicians, meanwhile, simply lack sufficient knowledge, comfort, or skill in communicating prognosis, and require training in this task.

This conventional narrative, however, depends on at least two questionable assumptions. The first is that an individual's prognosis—in the sense of a meaningfully accurate, precise estimate of the probability of living or dying—is actually known, that prognostic certainty is attainable. This assumption is problematic from both descriptive and normative standpoints. For most seriously ill individuals, evidence-based prognostic estimates are lacking. When they do exist, their precision is limited by inherent shortcomings in the empirical data and statistical methods used in their estimation. Furthermore, from a normative standpoint, evidence-based, objective probabilities strictly apply only to groups, not individuals; they are derived from and expressed in terms of the frequency of a given event in some population. Probabilities can be extrapolated to individuals, but in this conceptual leap they cease being objective and become subjective expressions of mental confidence, with no right or wrong answer. Indeed, the very idea of “individual” probability is logically incoherent; it is nonsensical to speak of the frequency of a single event (Hacking 1975). The prognosis of individuals remains not only unknown but unknowable, blurring the lines between denial and acceptance, optimism and realism. Certainty about the prognosis of any individual is an unattainable goal.

But equally questionable is the assumption that prognostic certainty is what dying persons really need in the first place. This is a prescriptive claim that can only be justified with reference to more fundamental moral values and conceptions of what a “good death” entails. The prevailing conception, based on the ethical principle of respect for patient autonomy, is that a good death is an informed death, and that prognostic knowledge is essential to being informed. In close alignment with behavioral economic theories of rational choice, this conception focuses on the cognitive value of prognostic information in helping persons judge which choice options have the greatest expected utility.

An alternative perspective on prognostic knowledge, however, is not cognitive but existential—pertaining to how one lives and copes with the daunting, ineffable prospect of one's nonbeing. From this perspective, a good death is not necessarily an informed death, and my father's experience was a case in point. From the time of his cancer diagnosis to his eventual death, he never once asked how long he had to live or what his chances of surviving were. He simply pushed ahead. This was my father's approach—his authentic approach and mode of being throughout his entire life. He lived for possibilities, not probabilities. In his final days, prognostic estimates and any theoretical, cognitive certainty they might have offered were all the more irrelevant to the real dilemma at hand: at one end lay the stark, certain necessity of death, at the other the possibility of life. For my father, the gist of impending death reduced to this dichotomy, not to some logically incoherent continuum of frequencies of an unrepeatable event.

The existential motif of necessity versus possibility extends beyond my father and his death. Søren Kierkegaard, the father of existentialism, viewed the tension between these two opposing aspects of reality as a defining problem of human life. Necessity and possibility, he argued, each produce a distinct type of despair that individuals strive to avoid by seeking the other extreme. Individuals respond to the “despair of necessity due the lack of possibility” by embracing possibility, a response that Kierkegaard (1849) captured vividly: “Procure me possibility, procure possibility! Possibility is the only saving remedy; given a possibility, and

with that the desperate man breathes once more, he revives again; for without possibility a man cannot, as it were, draw breath” (311).

Kierkegaard viewed faith in possibility as a primal existential need. For my father, it was all there was: the freedom to rise above the despair of necessity, to transcend the determinism of unseen tumors and cytokines that were robbing him daily of strength and life, to assert his existence. Paul Tillich (1952) called this transcendent, supra-cognitive state the “courage to be”: the self-affirmation of one’s being in spite of the threat of nonbeing. But in my father’s case this state could not have existed without prognostic uncertainty: the conscious awareness of ignorance about prognosis. It was prognostic uncertainty that created the possibility of life, opening the door to faith and hope rather than doubt and resignation. And it was prognostic silence, in turn, that enabled this uncertainty and was thus ultimately justified.

To be clear, I do not claim that prognostic information is always irrelevant, or that prognostic silence is justified for all dying persons in all circumstances. Prognostic information can be helpful when dying persons or clinicians demand ineffective interventions, or when they need to choose between multiple different treatment options. And apart from these conditions, some dying persons simply desire precise prognostic information and want to believe in it. I have witnessed individuals take the opposite approach to my father’s: seeking and placing complete faith in a prognostic estimate, embracing the necessity of death, fatefully closing off all possibility by foregoing life-sustaining treatment, even hastening the dying process based on prognostic information. Such information may also be valuable for other parties, such as family members or the health-care system as a whole. More precise prognostic information would have helped my brother, me, and our families prepare more efficiently for my father’s death. And it might have dissuaded his oncologist from offering an ineffective treatment, reducing health-care costs.

My focus, however, is on the existential needs of dying persons themselves, viewed from a different perspective than the prevailing medical narrative that treats the prognosis of individuals as known and a good death as an informed death. I have argued that prognosis is ultimately unknowable and that although precise prognostic information can be cognitively useful, it can also be existentially irrelevant. My overarching claim is that what many dying persons need most is not prognostic certainty but uncertainty, and that this need for uncertainty sometimes justifies prognostic silence.

Yet the nature of death resists definitive conclusions about any of these matters. Like the future, death is ultimately unknowable. There is no single true prognosis; I doubt there is one right approach to dying or that it lies within medicine’s purview to define it. What my struggle with my father’s death and the prognostic silence that preceded it have taught me is that uncertainty is a fundamental need for some dying persons, but even more so for those of us—clinicians, family members, loved ones—who care for them. Uncertainty helps us avoid imposing our own conceptions of a good death on anyone else. It makes us think twice before breaking the prognostic silence some persons keep as they die. More broadly, it forces us to acknowledge that none of our various explanatory narratives—medical,

psychological, philosophical—can ever fully capture the reality and meaning of living and dying.

This humble acknowledgment is hard for physicians who, from their earliest years of training in medical school, are tasked with the constant challenge of generating single right answers about the diagnosis, prognosis, and treatment of their patients (Fox 1957). The alluring but ultimately illusory ideal of precision medicine compounds this difficulty. Uncertainty, however, is not only constraining but liberating. It frees us from the tyranny of unrealistic expectations about the existence of singular, definitive answers and our ability to find them. It increases, rather than decreases, the precision of clinical work by helping us know when to refocus our medical lens away from problems it lacks the resolution to address. How an individual dying person should confront the ponderous prospect of nonbeing is one such problem. Uncertainty enables us to let go of our blinding preconceptions and to simply be silent, open to new possibilities and experiences of meaning.

Letting Go

At around 3:00 AM, approximately four months after my father's cancer was diagnosed, my brother called to report that my father was becoming increasingly lethargic, weak, and dyspneic after developing a worsening cough over the preceding few days. I took the first flight out in the morning, a few hours later. "Please hold on until I get there," I repeated to myself along the way, irrationally, worried that at any moment my journey would be interrupted with word that my father had already died. I avoided checking my phone as my plane landed and my taxi threaded through thick traffic to my brother's house.

I arrived in the afternoon to find my father unfortunately unresponsive, although fortunately in no apparent distress. Over the next several hours I sat with him, holding his hand, telling him how much I loved him. I've never been sure whether persons in this terminal state could really hear and register language, but I have always counseled family members to act as if it were possible. In any case it was all I could do. All the while, my father didn't move a muscle except for his breathing, which remained steady and deep like the ocean tides.

Into the night I sat and watched, while a branching stream of memories reaching back to my childhood replayed in my mind. Around 4:00 AM, my brother joined me at the other side of the bed, and we talked and watched together. About an hour later my brother decided to get some sleep and arose and came to my side of the bed. We hugged tight and cried; he told me what a great dad we had, and I told him how I had spent the night thinking exactly that. My brother then turned into the darkness and ascended the stairs to his room. Within moments, as I sat back down, my father's head and torso suddenly lunged towards me and he gasped, drawing in a single large breath then slowly exhaling, emptying his lungs completely. But there was no inspiration. I watched for a few more seconds, waiting, my own heart pounding as I felt the absence of his pulse, followed by the final fibrillations of life, and then, stillness. I called out to my brother who had not yet reached his room, and we stood there together with my father, marveling in silence.

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