

Hope for the Best, and Prepare for the Worst

Mr. J., a 40-year-old father of two young children, has metastatic non–small-cell lung cancer that has not responded to two different chemotherapy regimens. His physician, Dr. B., explains that the cancer is progressing. Mr. J. says, “Isn’t there something you can do? Please don’t give up on me.” Dr. B. pauses and says, “Well, there is an experimental protocol we could try.”

When faced with life-threatening illness, patients and physicians often feel that they must choose between hoping for disease remission and preparing for death. Mr. J. wants to fight the cancer in hope of living longer, and his physician is reluctant to discuss palliative care issues because she does not want to “destroy his hope” (1). Dr. B. knows that a patient in Mr. J.’s situation rarely benefits from third-line chemotherapy, and she also knows that by offering aggressive treatment she may be colluding with Mr. J. to avoid discussing the most likely prospect—that he is dying (2). Dr. B. is unsure how to proceed.

When patients and physicians discuss life-threatening illness by focusing exclusively on hope, they may miss important opportunities to improve pain and symptom management (3, 4), respond to underlying fears and concerns, explore life closure (5), and deepen the patient–physician relationship. The difficulty for physicians is acknowledging and supporting the patient’s hopes while recognizing the severity of the patient’s disease, thus offering an opportunity to discuss end-of-life concerns.

Hoping for a cure and preparing for potential death need not be mutually exclusive. Both patients and physicians want to hope for the best. At the same time, some patients also want to discuss their concerns about dying, and others probably should prepare because they are likely to die sooner rather than later. Although it may seem contradictory, hoping for the best while *at the same time* preparing for the worst is a useful strategy for approaching patients with potentially life-limiting illness. By acknowledging all the possible outcomes, patients and their physicians can expand their medical focus to include disease-modifying and symptomatic treatments and attend to underlying psychological, spiritual, and existential issues.

FRAMING THE DISCUSSION

This strategy of simultaneously hoping for the best and preparing for the worst may initially seem inconsistent and contradictory: How can you talk about chemotherapy *and* palliative care? Our strategy embraces the divided thinking many patients, families, and even health care providers have, which is often not logically consistent because of the profound ambivalence and vacillation they experience.

This strategy is derived, in part, from classic studies of human behavior during illness. Sociologists Glaser and Strauss (6) described patients who experienced an “open

awareness” of their impending deaths and discussed it explicitly with family and caregivers. Kubler–Ross (7) built on this work by describing stages of dying, culminating in a stage she called “acceptance.” However, most patients do not progress linearly through Kubler–Ross’s stages. Living with a terminal illness is often marked by ambivalence about being a dying person. Weisman (8) described a period of “middle knowledge,” in which patients vacillate between the state of continuing to live and plan and the state of preparing for death. Similarly, McCormick and Conley (9) interviewed patients who spoke of a “living–dying” period late in their illness. These studies and others (10, 11) indicate that vacillation between living and dying is common to many patients like Mr. J.

Using this strategy frames the discussion to include both living and dying. It may seem paradoxical to simultaneously explore living and dying, since these states are mutually exclusive in common parlance. However, this framing may enable Dr. B., Mr. J., and Mr. J.’s family to have a deeper conversation than if they focused just on dying or living. The following guidelines are useful.

1. Give Equal Air Time to Hoping and Preparing

Dr. B. wants to be empathic and realistic: I want to work with you, and I will do everything I can to optimize your chances. I am hoping for the best. I think that, at the same time, we need to prepare for the worst in case the treatment is not effective.

Mr. J.: Hope is really important to me.

By articulating hope and preparation at the outset, Dr. B. gives Mr. J. permission to discuss a wide range of topics. An introductory statement such as “I have found it helpful to hope for the best and, at the same time, prepare for the worst” allows the patient to discuss the topic he feels is most important or is most comfortable with. For patients like Mr. J., who want to discuss hopes first, we recommend following the patient’s lead to fully explore hopes and place those hopes in the context of the patient’s disease process. Other patients may need to prepare for their potential death before they can commit wholeheartedly to active treatment.

2. Align Patient and Physician Hopes

Dr. B.: Could you tell me more about what you are hoping for? That will help me do a better job for you.

There are legitimate reasons why physicians should encourage patients to hope, such as disease remission or improvement in health status. Hope is a critical element for coping with illness (12). Most patients expect and want physicians to be advocates for health and longevity. Even if the media frequently exaggerate the power of medicine, many patients have beaten the odds. Patients frequently cite hope as the most important element of their coping

and seek clinicians who will search every avenue of hope (13).

Physicians also want to hope for the best. Many physicians pursued medicine because they wanted to cure diseases, make patients feel better, and help relieve suffering (14). Articulating hopes for extending a patient's life can affirm this aspect of medicine. Some medical therapies, such as chemotherapy, make patients feel worse in the short run. To give these therapies day after day requires that oncologists believe in their ability to provide long-term benefit. Providing hope to patients is psychologically gratifying because patients and families are often grateful to doctors who hope. Shared hopes offer physicians an opportunity to align with their patient.

3. Encourage but Do Not Impose the Dual Agenda of Hoping and Preparing

Dr. B.: It's good for me to know about your hopes. It helps me get to know you better. Do you also want to talk about your concerns if things do not go as we hope?

Mr. J.: I'm really committed to trying this new treatment, and I feel like you are kind of giving up on me with this "preparing for the worst" stuff.

Dr. B.: I share your hope that the new treatment will benefit you. I want you to have the best medicine available. I talk about hoping for the best and preparing for the worst with all my patients who are seriously ill. Preparing for the worst doesn't mean I'm giving up on you; it helps me arrange the best medical care for you, no matter what happens.

When physicians initiate a conversation about preparing for the worst, patients and family members may react with fear, sadness, anxiety, or anger. Blocking or ignoring such emotions sends a nonverbal message that the physician is uncomfortable in discussing the worst and discourages patients from honestly discussing their concerns (15).

There can be positive consequences for patients who prepare for the worst, which physicians can underscore, and these can be powerful motivators. By preparing for the worst—by making a living will, naming a health care proxy, preparing financial matters, or settling family affairs—patients can address fears, clarify priorities, and strengthen relationships with loved ones, all components of a good death identified in empirical studies of patients with life-threatening illnesses (16, 17). Furthermore, some patients may be thinking about the worst but are afraid to discuss it for fear of frightening their family or disappointing their physician. One study indicates that unarticulated concerns correlate with increased anxiety and depression (18). Naming and discussing these concerns, which often deal with spiritual and existential issues, is an important first step for patients.

Physicians can also benefit from discussing the worst. These discussions allow physicians to feel that they are being honest with patients and, if done in the context of a supportive relationship, can increase patient trust. Patients and families who prepare for a range of outcomes may be

less likely to blame their physicians for the consequences of disease progression.

4. Support the Evolution of Hope and Preparation over Time

Mr. J.: I don't want to think about preparing for the worst.

Dr. B.: It sounds like this is hard to think about.

Mr. J.: You bet it is.

Dr. B.: I wonder if you could say what makes it hard to think about?

Mr. J.: [pause] I'm worried that my wife won't be able to deal with this.

Knowing why a patient is reluctant to discuss these matters is important data for the physician. It may be enough to note the patient's hesitance about the discussion and plan to return to the issue at a future visit. Often the seed is planted even if it is not specifically discussed. Mr. J.'s willingness to talk about preparing for the worst may slowly increase over successive discussions as he begins to trust that his physician will hope and prepare at the same time.

Time the initial discussion early in the illness, and revisit the issues regularly. Talking about hope and preparation allows "big picture" discussions to begin. By regularly visiting the issues, physicians can normalize the idea that talking about death is one aspect of discussions between a patient and physician. The issues can then be revisited at times when a change in strategy is contemplated and the relative emphasis on relief of suffering and treatment of disease is brought into question. Time and disease progression may enable a patient to acknowledge his illness and the potential consequences. A physician may need to be more direct late in the patient's illness, while acknowledging that these topics are difficult. By revisiting hope and preparation regularly during the illness, Dr. B. can enable Mr. J.'s thinking to evolve and foster constructive ways of coping. Physicians should judge success in communication by the quality and depth of discussion and the adequacy of the plans jointly developed to guide medical care. However, if a patient has made reasonable plans but does not wish to talk in depth about dying, that patient's desires should be respected.

5. Respect Hopes and Fears, and Respond to Emotions

Mr. J.: You know, I'm really worried about my wife. I'm worried about leaving her alone.

Dr. B.: It sounds like you care a great deal about her.

Physicians can use communication strategies of responding to emotions, including acknowledgment, exploration, legitimation, and empathy (19) (Table). These strategies enable physicians to frame their concerns for the patient relative to the patient's concerns (*Mr. J., I can see that taking care of your family is a major priority, and I have some ideas about how to do that in case the treatment doesn't go the way we hope.*). This framing can help patient and physician reach common ground. Most patients want to

Table. Responding to Hopes and Fears*

Patient Says:	Physician Responds:
"I hope that I can live a little longer."	"I hope you can live longer, too. What would be most important for you in that time?"
"I hope that the treatment will help me."	"I'm also hoping that the treatment will help you. If it works, what will be most important for you to do? I wonder, also, if you would be willing to talk about what we should do in case the treatment doesn't work?"
"I'm concerned that talking about the worst will be overwhelming."	"Hmmm. . . . Talking about the worst can be frightening at first, but most of the patients I have worked with have found it helpful in the long run."
"I'm worried that talking about the worst would be giving up."	"I understand your concern, but we are not talking about giving up on treatment. We are asking you to consider what would be most important if treatment does not work as we both hope."
"I don't want to talk about what I'm worried about."	"Okay. I realize that talking about worries can be a hard thing to do. If you do want to talk about these issues in the future, I would be open to it."

* These examples show how physicians can respond to both hopes and fears as they discuss hoping for the best and preparing for the worst with their patients. To use this strategy effectively, physicians should explore patients' hopes and fears and respect patients' boundaries. Note that the suggested physician responses do not move immediately toward solving problems or reassuring. Premature reassurance can make patients feel their concerns are not heard. These responses suggest ways to deepen the conversation and better understand patient concerns.

hear their physician's true opinions and recommendations as long as the physician is not too blunt (20, 21). Compassion can take the form of giving recommendations in light of what the physician knows about the patient's values, medical situation, goals, and fears. A physician need not fully share a patient's hopes or fears to respect, learn about, and respond to them.

Physicians often have emotional responses to their patients, and these emotions shape their relationship with the patient and family. These emotions, if unmonitored, can influence the physician-patient communication and relationship in unintended ways. For example, physicians may feel like the patient "does not get it" and feel angry that they are being asked to provide care that is unlikely to work (22). Sometimes a physician's emotions can be a clue to how the patient is feeling; other times, physicians may come to understand that they are reacting to personal feelings of their own about death and dying (23). When trying to sort out one's own strong reactions, conversation with a trusted colleague can be clarifying.

OTHER CLINICAL SCENARIOS

Not every patient approaches a life-threatening illness like Mr. J. A patient who primarily prepares for the worst might benefit from a physician invitation to hope for the best. For example, a 65-year-old woman with breast cancer that is estrogen receptor positive and metastatic to bone but not visceral organs says that she is terrified of dying in pain and, consequently, is stockpiling pain medication. Her physician might explore this fear and learn that the patient had a difficult experience with a close friend who died of cancer and that her other fears include missing her first grandchild's birth expected in 3 months. The physician could reassure her and also invite her to hope (*I can*

assure you that sophisticated pain control will be available if you need it. I think we can also hope that the tamoxifen will control the cancer for many months with minimal toxicity. It is entirely possible to hope that you will be present when your grandchild is born.)

This approach is also applicable to patients with non-cancer illnesses. For example, a 55-year-old man with end-stage congestive heart failure who is waiting for a heart transplant might also benefit from a discussion about hoping and preparing (*I am hoping that a heart will become available for you, and we want to do everything we can to keep you ready. I also want to be prepared if a heart does not come up and your own heart gets worse.*). The question "If time turns out to be short, what would be most important for you to accomplish?" may facilitate an important conversation.

PITFALLS OF FOCUSING EXCLUSIVELY ON HOPING OR PREPARING

Hoping and preparing minimizes the weakness of each strategy on its own. Focusing only on hope may leave patients unaware of their limited life expectancy (24). Such patients are more likely to choose life-prolonging therapies such as cardiopulmonary resuscitation in situations where these therapies are rarely effective (25, 26). Thus, when physicians focus only on hope, patients may unrealistically focus their time and energy on treatments that are unlikely to work. Physicians who focus exclusively on hope also may feel that they have not been honest with patients, which can make it more difficult for them to confront the limitations of medicine (22). These physicians withdraw when it becomes clear that a patient is dying; patients sense

withdrawal, feel abandoned, and may respond by demanding even more medical attention (27).

LIMITATIONS

This dual-track approach may not work for everyone. Patients may not wish to live with the cognitive and emotional dissonance of hoping for the best and preparing for the worst. Some cultures place negative values on talking explicitly about death or potential bad outcomes, feeling it is dangerous, harmful, and even cruel. Once the meaning of such conversation is fully understood, physicians should attempt to find alternative, culturally appropriate processes that may not involve open discussion to make critical end-of-life decisions (30, 31).

This approach requires that the physician maintain dual roles, providing two kinds of coaching: optimism (*Let's hope*) and realism (*Let's prepare*). Physicians using this approach will need to be careful about checking in with the patient's emotional state to ensure that the patient understands the physician's intention. Physicians may need to explain this strategy to other clinicians and family members, who may be concerned that the approach presents a confusing, mixed message.

Other physicians may feel that the terminology "preparing for the worst" is too harsh, casting death as the enemy or suggesting that death always is accompanied by severe suffering. A more tempered phrase, such as "preparing for the possibility that the treatment fails" may allow patient and physician to gradually work toward a common understanding of the difficult issues presented by dying.

Finally, there are few data linking hope and preparation to other outcomes. Although descriptive data indicate the importance of both of these approaches, no studies have examined how supporting hope and preparing for death might affect medical outcomes such as survival, quality of life, symptom management, and quality of death.

CONCLUSION

Physicians often deal with hope as something they must embrace or negate completely. But this exclusive focus on hope constricts options for discussing how a patient, family, and physician can work together with a life-threatening illness. Embracing a dual approach of hoping for the best and preparing for the worst helps physicians join with patients and families, yet plan medical care that is responsive to a range of potential outcomes for the patient. These conversations can enrich the patient-physician relationship and provide a fresh source of meaning for the work of medicine (32, 33).

Anthony L. Back, MD

Veterans Administration Puget Sound Health Care System
University of Washington
Seattle, WA 98108

Robert M. Arnold, MD
University of Pittsburgh
Pittsburgh, PA 15213

Timothy E. Quill, MD
University of Rochester
Rochester, NY 14642

Ann Intern Med. 2003;138:439-443.

Acknowledgments: The authors thank Dr. Susan Block for her helpful suggestions about the role of ambivalence.

Grant Support: Drs. Back and Arnold are Faculty Scholars of the Project on Death in America. Dr. Arnold was also supported by the Greenwall Foundation, Ladies Hospital Aid Society of Western Pennsylvania, and the LAS Trust Foundation.

Requests for Single Reprints: Anthony Back, MD, Veterans Administration Puget Sound Health Care System, 1660 South Columbian Way S111, Seattle, WA 98108; e-mail, tonyback@u.washington.edu.

Current author addresses are available at www.annals.org.

References

1. Delvecchio Good MJ, Good BJ, Schaffer C, Lind SE. American oncology and the discourse on hope. *Cult Med Psychiatry*. 1990;14:59-79. [PMID: 2340733]
2. The AM, Hak T, Koeter G, van Der Wal G. Collusion in doctor-patient communication about imminent death: an ethnographic study. *BMJ*. 2000;321:1376-81. [PMID: 11099281]
3. Ersek M, Kraybill BM, Pen AD. Factors hindering patients' use of medications for cancer pain. *Cancer Pract*. 1999;7:226-32. [PMID: 10687591]
4. Cleland CS, Gonin R, Hatfield AK, Edmonson JH, Blum RH, Stewart JA, et al. Pain and its treatment in outpatients with metastatic cancer. *N Engl J Med*. 1994;330:592-6. [PMID: 7508092]
5. Byock IR. The nature of suffering and the nature of opportunity at the end of life. *Clin Geriatr Med*. 1996;12:237-52. [PMID: 8799345]
6. Glaser BG, Strauss AL. *Awareness of Dying*. Chicago: Aldine Publishing; 1965.
7. Kubler-Ross E. *On Death and Dying*. New York: Macmillan; 1969.
8. Weisman A. *On Dying and Denying: A Psychiatric Study of Terminality*. New York: Behavioral Publications; 1972.
9. McCormick TR, Conley BJ. Patients' perspectives on dying and on the care of dying patients. *West J Med*. 1995;163:236-43. [PMID: 7571586]
10. Barnard D, Boston P, Towers AM, Lambrinidou Y. *Crossing Over: Narratives of Palliative Care*. New York: Oxford Univ Pr; 2000.
11. Kuhl D. *What Dying People Want: Practical Wisdom for the End of Life*. New York: PublicAffairs; 2002.
12. Herth K. Fostering hope in terminally-ill people. *J Adv Nurs*. 1990;15:1250-9. [PMID: 2269747]
13. Quill TE, Cassel CK. Nonabandonment: a central obligation for physicians. *Ann Intern Med*. 1995;122:368-74. [PMID: 7847649]
14. Crawshaw R, Rogers DE, Pellegrino ED, Bulger RJ, Lundberg GD, Bristow LR, et al. Patient-physician covenant. *JAMA*. 1995;273:1553. [PMID: 7739086]
15. Maguire P. Improving communication with cancer patients. *Eur J Cancer*. 1999;35:1415-22. [PMID: 10673972]
16. Steinhauer KE, Christakis NA, Clipp EC, McNeilly M, McIntyre L, Tulsky JA. Factors considered important at the end of life by patients, family, physicians, and other care providers. *JAMA*. 2000;284:2476-82. [PMID: 11074777]
17. Singer PA, Martin DK, Kelner M. Quality end-of-life care: patients' perspectives. *JAMA*. 1999;281:163-8. [PMID: 9917120]

18. Heaven CM, Maguire P. Disclosure of concerns by hospice patients and their identification by nurses. *Palliat Med.* 1997;11:283-90. [PMID: 9373579]
19. Quill TE. Recognizing and adjusting to barriers in doctor-patient communication. *Ann Intern Med.* 1989;111:51-7. [PMID: 2660647]
20. Quill TE, Brody H. Physician recommendations and patient autonomy: finding a balance between physician power and patient choice. *Ann Intern Med.* 1996;125:763-9. [PMID: 8929011]
21. Curtis JR, Wenrich MD, Carline JD, Shannon SE, Ambrozy DM, Ramsey PG. Understanding physicians' skills at providing end-of-life care perspectives of patients, families, and health care workers. *J Gen Intern Med.* 2001;16:41-9. [PMID: 11251749]
22. Quill TE, Suchman AL. Uncertainty and control: learning to live with medicine's limitations. *Humane Med.* 1993;9:109-20. [PMID: 11656250]
23. Meier DE, Back AL, Morrison RS. The inner life of physicians and care of the seriously ill. *JAMA.* 2001;286:3007-14. [PMID: 11743845]
24. Lamont EB, Christakis NA. Prognostic disclosure to patients with cancer near the end of life. *Ann Intern Med.* 2001;134:1096-105. [PMID: 11412049]
25. Weeks JC, Cook EF, O'Day SJ, Peterson LM, Wenger N, Reding D, et al. Relationship between cancer patients' predictions of prognosis and their treatment preferences. *JAMA.* 1998;279:1709-14. [PMID: 9624023]
26. Emanuel EJ, Young-Xu Y, Ash A, Gazelle G, Levinsky N, Moskowitz M. How much chemotherapy are cancer patients receiving at the end of life? [Abstract] Proceedings of the 37th Annual Meeting of the American Society of Clinical Oncology, San Francisco, CA; 12-15 May 2001. Abstract no. 953.
27. Shapiro A. *The Vigil.* Chicago: Univ of Chicago Pr; 1997.
28. Waisel DB. The hazards of "hanging crepe" or stating overly pessimistic prognoses. *J Clin Ethics.* 2000;11:171-4. [PMID: 11056876]
29. Siegler M. Remarks on 'crepe hanging'—or ethics in everyday practice. *Am Med News.* 1977;20:22. [PMID: 11664719]
30. Kagawa-Singer M, Blackhall LJ. Negotiating cross-cultural issues at the end of life: "You got to go where he lives." *JAMA.* 2001;286:2993-3001. [PMID: 11743841]
31. Crawley L, Payne R, Bolden J, Payne T, Washington P, Williams S, et al. Palliative and end-of-life care in the African American community. *JAMA.* 2000;284:2518-21. [PMID: 11074786]
32. Quill TE, Williamson PR. Healthy approaches to physician stress. *Arch Intern Med.* 1990;150:1857-61. [PMID: 2393317]
33. Remen RN. Recapturing the soul of medicine: physicians need to reclaim meaning in their working lives. *West J Med.* 2001;174:4-5. [PMID: 11154646]

Personae

In an effort to bring people to the pages and cover of *Annals*, the editors invite readers to submit photographs of people for publication. We are looking for photographs that catch people in the context of their lives and that capture personality. *Annals* will publish photographs in black and white, and black-and-white submissions are preferred. We will also accept color submissions, but the decision to publish a photograph will be made after the image is converted to black and white. Slides or prints are acceptable. Print sizes should be standard (3" × 5", 4" × 6", 5" × 7", 8" × 10"). Photographers should send two copies of each photograph. We cannot return photographs, regardless of publication. We must receive written permission to publish the photograph from the subject (or subjects) of the photograph or the subject's guardian if he or she is a child. A cover letter assuring no prior publication of the photograph and providing permission from the photographer for *Annals* to publish the image must accompany all submissions. The letter must also contain the photographer's name, academic degrees, institutional affiliation, mailing address, and telephone and fax numbers.

Selected Personae submissions will also appear on the cover of *Annals*. We look forward to receiving your photographs.

Christine Laine, MD, MPH
Senior Deputy Editor

Current Author Addresses: Dr. Back: Veterans Administration Puget Sound Health Care System, 1660 South Columbian Way S111, Seattle, WA 98108.

Dr. Arnold: Section of Palliative Care and Medical Ethics, MUH 200 Lothrop Street 932, Pittsburgh, PA 15213.

Dr. Quill: Palliative Care Program, University of Rochester School of Medicine, Box 601, 601 Elmwood Avenue, Rochester, NY 14642.