Bad News: Delivery, Dialogue, and Dilemmas

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• The narrative from a real patient encounter is used to illustrate the powerful effect that delivering bad news can have on both patient and physician. The meaning of bad news to the patient may be quite different than the medical or the personal meaning to the physician. Differences in perceptions must be explored and understood before the common ground necessary for joint decision making is established. Initial patient responses can be divided into three categories: (1) basic psychophysiological (flight-flight or conservation-withdrawal), (2) cognitive, and (3) affective. Responses very considerably depending on the meaning of the diagnosis to the patient, the degree of immediate threat, and the patient's previous experience with illness. Desired outcomes of the initial meeting include (1) minimizing avoidance as a defense for both patient and physician; (2) achieving a common perception of the problem; (3) giving information tailored to the immediate needs of the patient; (4) addressing immediate medical needs, including the risk of suicide; (5) responding to immediate discomforts; and (6) establishing a focus for follow-up. Though all clinicians deliver bad news, few have had formal training or open exploration of the potential impact of the experience.

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A 37-year-old man who used intravenous drugs was diagnosed with having human immuno-deficiency virus (HIV). He and his wife were unmarried and had not had sexual relations in 3 years. His wife was an independent, family-oriented, devoutly Christian woman with three children who worked as a nurse's aide. She had a prolactin-secreting pituitary adenoma for which she had previously accepted medical treatment (transnasal-surgery) in the past. She preferred to eat her meals in God, taking the medication only when her prolactin level became markedly elevated. She and I (T.L.Q.) had known each other for 6 years, and our recurrent complex discussions resulted in a close relationship where each of our perspectives was understood and respected by the other. When her husband was diagnosed with HIV, she came to see me to discuss the situation and assess her risk of the test, and the difference between HIV and AIDS. She continued to be tested, but what she would do if her test were positive, she did not know, but I don't think God would do this to her. We went ahead with a planned follow-up visit where the results were discussed.

The results showed she was HIV infected, feeling sad for both her as a person and for the rest of the epidemic is truly reaching all walks of life. I dread the meeting where I would deliver the result, not knowing how she would respond, and I fear the ramifications of her diagnosis in her family, and her sense of who she was. What follows is transcript of the first minutes of our meeting.

PATIENT: Is it AIDS?
DR. QUILL: I'm afraid it is.
PATIENT: Oh my. Dr. Quill. Oh my God!
DR. QUILL: I was shocked too.
PATIENT: Oh God, oh Lord have mercy. Oh God, don't let this happen to me. Oh my God, oh Lord have mercy. Oh my children. Oh God, oh Lord have mercy. Oh God, why is this happening to me? Why did He do this to me? Why did He do this to me? Oh my God, oh Lord have mercy. Oh my God, Jesus.

DR. QUILL: You're still asking at this point, okay.

PATIENT: You don't know how long I've had this. Dr. Q:
DR. QUILL: I don't know.

PATIENT: I can't sit. (She walks around room.)

DR. QUILL: It's okay.

PATIENT: Why did He do this to me? Why? What have I done? Why does He do this to me? Why? Why? Why? Why? Why? Why? Why? Why? Why? Why? What is going to happen to all of my children? I won't be able to take care of my grandchildren. I just had another granddaughter. I can't see her... I won't be able to see the baby, I won't be able to hold her... I can't take care of her... I can't talk to her... I won't be able to see... I won't be able to talk to her... I won't even have a future. Everything I
DR QUILL: No, that's not so.

PATIENT: Yes they will, 'cause I feel that way about people. You don't know what to say to them and what to do. Oh God.

DR QUILL: What we have to do is to learn some things about it . . . even though it's scary it may not be as scary as you think. Okay?

PATIENT: Oh my God. Oh my God. I hate him. I hate him. I hate the ground he walks on. I hate him. Dr Quill. I hate him. He gave this to me. I hate him. He took my life away from me. I have been robbed. I feel as if I have been robbed of a future. I don't have nothing.

DR QUILL: There is a future for you.

PATIENT: They don't even have a cure for me.

DR QUILL: There's a lot of work going on right now, and you can have the injection for a long time before you get sick. There is a lot of research going on.

PATIENT: I read about it. I have a friend with it. I went over to the university . . . Since you told him he had AIDS, he has been at my house and I feel so sorry for him. I was being nice to him. Oh my God, my God. It just doesn't pay to be nice. It doesn't. What do you get out of it?

DR QUILL: Neither you nor he knew that there was a risk back then.

PATIENT: Another cross to bear.

DR QUILL: You never did anything wrong.

PATIENT: What am I going to tell my children when they are old enough to tell them?

DR QUILL: Before you tell them anything, you are going to learn a lot about this.

PATIENT: I can't go home. I can't even say here. I'm so scared. Oh my God. I know that you were going to tell me this. I always liked you. I didn't want you to tell me this. Oh God. I don't know if I can deal with this. I don't know. Dr Quill, I'll deal with this.

DR QUILL: You've worked through this before. It's going to be hard, but it may not be as bad as you think. Okay? I think what you have to do . . .

PATIENT: I got my church. Dr Quill. I can't let them see me like that. I can't do it. I would rather . . . because I can't let our church see me like this. They mean a lot to me. Oh, Dr Quill, and my daughter. Oh, I won't see my daughter and my baby.

DR QUILL: You are still the same person. Okay?

PATIENT: Why is He doing this to me?

DR QUILL: I don't know. You are still the same person. What we have to do is eventually learn as much as you can about this. The odds are that you are going to stay healthy for a long time. Okay? You are still very healthy right now.

PATIENT: What are you telling me? I still have a chance to live? Can I live?

DR QUILL: That is possible.

PATIENT: How can you be sure when you don't even know what the cure is for?

DR QUILL: A couple of things. Okay? We don't think you've had this very long a couple of years at the most. Alright. A lot of people believe that the virus can stay around for many years before it produces many problems. Sometimes 6 or 8 years. There is a lot of research going on now to try to find ways to treat it.

PATIENT: Oh God. Lord Jesus.

DR QUILL: You may have a lot of these before we have to deal with this. I think the first thing we have to do is probably get some further blood tests. We should be able to tell you if you are okay and how much we know even though we think we know how you got it. We may simply repeat it to be 100%, 100% sure, even though they repeat it once. I think there's a way to do it because the only way that you could have gotten it is from your husband. I think we ought to repeat it even though we know that it is probably true.

PATIENT: I don't know if I can live with myself . . . in my bed right now. I don't like him. Dr Quill. I don't even want to stand by him.

PATIENT: My children.

DR QUILL: It's very scary. Also, there are a lot of things we can do.

PATIENT: Oh. Lord have mercy. Then I have the second thing.

DR QUILL: Like your primary tumor; it has been there for years. It doesn't . . .

PATIENT: It's not the same.

DR QUILL: No, it's not the same. If the tumor gets worse, we know what the treatment is.

PATIENT: It's the same. It can't be cured. You talking about something they never come up with. Never come up with a cure for. I've got nothing. All they can do is treat whatever comes along. Like a cold, or pneumonia. Small like that—which is all.

DR QUILL: That's right. But right now there are millions and millions of dollars being poured into research and that's what we have to hope for.

PATIENT: It doesn't make me feel good.

DR QUILL: I wish I had something more easy to tell you, but I think there are a lot of folks who are in the same shoes that you're in and they are all hoping. They are doing all sorts of ways to cope. That's what we have to figure out.

PATIENT: Dr Quill, will you still be my doctor?

DR QUILL: Absolutely, I will.

PATIENT: You promise?

DR QUILL: Absolutely. We'll meet very regularly so we know what's going on.

PATIENT: Okay, alright. I'm so scared. I don't want to die. I don't want to die, Dr Quill, not yet. I know I got to die, but I don't want to die.

DR QUILL: We've got to think about a couple of things . . .

We both felt overwhelmed by the news and the encounter. With great difficulty, I allowed her rage and terror to be expressed, yet also to find some boundaries. I was concerned for her, and needed to be reassured before she left that there was a basic plan. Through the intense emotional expression, she raised several basic questions that needed to be addressed: 1) Will you still be my doctor? (Will I be alone?) 2) How contagious (reproductive) am I? 3) Am I still the same person? 4) When am I going to die? 5) How can I talk to my family, friends, and children? Though these questions were by no means simple, struggling to answer them began to give some definition to her problem.

My struggle to respond adequately caused me to reflect on the process of delivering bad news. In spite of the fact that all clinicians do this to some degree on a regular basis, there is little medical literature about it, and almost no formal training. As background for this article, we expanded our research into the psychology literature about responses to overwhelming stress and crisis intervention. We have also conducted experimental workshops with expert clinicians to learn about their beliefs and strategies. The schema presented represents our synthesis of these data with our own clinical experience, both as a general internist (T.I.E.Q.) and coordinator of a home hospice program (F.L.E.). It emphasizes the initial delivery, when the patient's first comes to grips with a new problem, rather than needs and strategies which evolve over time.

ADVANCE PREPARATION

Advance knowledge about the patient's strengths, weaknesses, and coping style can be invaluable in deciding how to present bad news. This patient's spiritual beliefs, family support from her children, and fierce independence were clear
ambivalent feelings and use of denial about medical diagnosis and treatment with her primary adenoma were potential sources of concern. Our advance discussions concerning her knowledge and beliefs about HIV allowed her to begin anticipatory grief work. They also allowed her physician to begin to understand the potential meaning of the news. Her thoughts about what she would do if infected ("I don't know, but I don't think God would do this to me") was potentially ominous and might have been explored further in advance.

The physician is usually the first to get the news and may have to grieve before meeting with the patient. Particularly if there has been a close physician-patient relationship in the past. With this patient, my own and feelings forced me to seek out one of my close colleagues and explore my own reactions to the news before proceeding. I needed to explore my own grief before I encountered hers. It is also important for the physician to ensure that the information about the diagnosis is accurate and that he is knowledgeable about its medical implications, including prognosis and further treatment options. If the patient has a condition with which the physician is unfamiliar, then the physician must learn enough about it to be informative and answer general questions about prognosis and therapeutic options in this initial meeting.

TIMING

Bad news should be delivered in a face-to-face encounter in a private setting with time set aside to allow the patient and family to respond and ask questions. It is not a task to be delegated or to be done in an indirect way, such as over the phone. Though this patient did not want to come in to hear the news, she was strongly encouraged to make an appointment. Advance agreements about how and when to share the results are helpful, as are advance considerations of how directly or indirectly to involve significant others. This patient clearly wanted to receive the news alone and then consider the difficult process of involving her family only if the test were positive.

Often questions are raised by physicians or families about whether the patient is medically or psychologically strong enough to handle bad news. Though there may be exceptional circumstances where delivering the bad news directly to the patient should be delayed or avoided, this requires careful analysis of who is really being process. If the patient is competent, some advance assessment of the patient’s wish to be informed should be made. A patient's direct request for information creates an obligation to inform that takes precedence over a family member's or a physician's fear of doing the patient harm unless the evidence suggesting harm is very clear. It is not the physician’s role to protect a patient from the truth about his or her condition or the ensuing grief. Exploring the family's fears and concerns, and also informing the family about the necessity for responding to the patient's questions, may allow the family to grieve and prepare for the patient's being told. If this short delay is not likely to harm the patient, then it may be justified in the interest of overall patient and family well-being.

DELIVERING THE NEWS

An initial assessment of the patient's readiness to hear the news is the first step. This patient requested the results as I walked into the room ("Is it AIDS?") and could read the information clearly and simply in language that was comprehensible to the patient. Hopefully, the information was explored in advance when the purpose was being considered. The complex meanings that may have for words such as tumor, cancer, malignancy, infection, or AIDS mean that common understanding be ensured without joint exploration.

Other patients do not want to hear the news right away, and one may take the time to explore how they are feeling or the shape of the test results is extremely important. First, it allows the patient to control the flow of information and to have time to absorb himself or herself before hearing the news. It helps the physician understand more about the patient’s style and about the potential impact of the news delivered. Unless the patient specifically requests that the news (a request that needs in-depth exploration understanding), the physician eventually should deliver the news in a clear, sensitive manner.

If the news to be delivered is complex or when the patient feels overwhelmed, the physician should avoid the temptation to deliver all information at once. Each piece of news, from the diagnosis to each of its implications, may move in profound impact on the patient, so the patient should time and opportunity to respond. This is particularly when the patient’s self-image and world view is severely threatened.

Though the patient’s belief a disease and previous reactions to stressful situations help predict his or her response, the physician’s reaction is vital, particularly if the news is perceived by the patient as overwhelming.

INITIAL PATIENT RESPONSE

Patients will respond to their perception of the news, which may or may not be congruent with the medi- ty.

These discrepancies, if not recognized and worked through, can create profound barriers between physician and patient. This woman’s perception of her diagnosis as a death sentence and a disease that would lead her into a pariah was overwhelming: "I don't want to live. Everything I know is that you gonna die. When is there to do? What if I’m a walking time bomb, will be scared to even touch me or say anything to me or be with me." Each perception had some truth and some distortion. The challenge for the clinician is to respond empathically to the devastating feelings and perceptions, while simultaneously beginning to correct distortions so that the loss could be better understood and coping can begin. In this patient, I followed freely, whereas in others emotions may be "to fall" or threatening to be expressed. In the latter instance, the physician might ask, "What is the most troubling part?" in an effort to understand the patient’s experience.

When the threat of the diagnosis is severe, basic responses are elicited that fall into three categories: (1) basic psychophysiological, (2) cognitive, and (3) emotional. The two basic psychophysiological mechanisms are the flight response and the conservation-withdrawal response, which correspond to activation of the sympathetic and parasympathetic nervous system, respectively.
wanted to flee and began pacing around the small examination room, unable to sit still. I wanted to give her room to pace, but I was also fearful that if she fled she might harm herself or find herself completely alone without any direction when the high-energy state wore off. By being allowed to pace and freely express herself, she was eventually able to accept some personal contact and information to help put her losses in perspective, and we were able to make a basic plan for follow-up.

An example of the conservation-withdrawal response would be a patient who became withdrawn and silent on hearing the news. Cognitive processes in this state are very limited, so patients often report feeling numb and having little recollection of the content of discussions beyond the initial news. In other species, this response may have considerable survival value when the creature is severely threatened ("playing possum"). Expectations in terms of information exchange need to be scaled down considerably once a patient enters a conservation-withdrawal state. In the extreme, a patient could become hyporesponsive from vasovagal syncope, attesting to the strong physiologic consequences.

There are five basic cognitive coping strategies: denial, blame, intellectualization, disbelief, and acceptance. This patient used denial as a cognitive coping strategy with her pulmonary edema, allowing her to lead a very full, untroubled life without treatment in spite of substantial gait disturbances. When confronted with her HIV diagnosis, her initial cognitive responses were somewhat disorganized but dominated by blame of her husband and God. She did not overly feel guilt but openly wondered how this could happen to her after leading such a good Christian life. The cognitive response that physicians are most comfortable with is intellectualization. Many patients (often to the relief of their physician) will seek information to control the emotional impact of the diagnosis. Though the physician should respond to requests for information, he or she should be aware that complex information may not be retained, in part because of the patient's affective state and consequent cognitive disorganization created by the initial news. If the patient's questions and quest for information become overly aggressive, they may represent an indirect expression of anger or blame that may need more direct exploration.

Affective responses will be present when anyone receives bad news. These may include anger (rage), fear (terror), anxiety, hopelessness, hopelessness, shame, relief, or guilt. For this patient, the overwhelming affects were overtly expressed, whereas for others they may be hidden to the patient, the physician, or both. Her initial affects were consistent with the fight-flight response, a mixture of rage, terror, and fear. The feelings flowed, giving tremendous power to her cognitive responses and a frightening reality to having one's world and self-image under siege: "Oh my God. Oh my God. I hate him. I hate him. I hate the ground he walks on. I hate him. Dr. Quill. I hate him. He gave this to me. I hate him. He took my life away from me. I have been robbed. I feel as if I have been robbed of a future. I don't have nothing."

Other patients may become acutely anxious or may be dominated by feelings of hopelessness ("There is nothing I can do") or hopelessness ("There is nothing anyone can do"). This patient's powerful affect was unmistakable, but in others it may be more subtle or covert. If strong affects are present but persistently unaddressed, they may limit a patient's ability to cope effectively with his or her illness.

INITIAL PHYSICIAN RESPONSE

The patient's perceptions about his or her illness, as well as the initial cognitive and affective responses, must be explored before substantial effects at patient education and informed decision making can proceed. The depth of this exploration will depend on the strength of the patient's responses and distortions, the medical necessity for rapid decision making, and the physician's interpersonal skills. If the physician is unable to undertake this task, it should be specifically delegated to a skilled person who has knowledge about the disease and experience working with patients.

To understand and respond to the patient's initial responses and distortions, the physician must listen, acknowledge, legitimate, explore, and empathize; these communication skills are described in detail elsewhere. Exploring, tolerating, and listening to a patient's responses to bad news are perhaps the most vital steps. To begin to relieve a patient's suffering, the physician must have thoroughly explored the patient's unique experience of pain and the meaning of the loss. This is particularly difficult when part of the response is anger and some of the blame is focused directly or indirectly on the physician. Feelings of hopelessness and despair may also be hard for physicians to tolerate, particularly when the patient has a condition where there are severe limits on the effectiveness of biomedical intervention. By hearing and attempting to understand and empathize with a patient's pain and struggle, the physician can help the patient feel less alone and therefore less overwhelmed, hopefully creating the foundation on which the patient can begin to face the problems ahead.

Not all patients will respond initially with cognitive distortions or strong affective responses. Some will simply want to know the medical facts and readily make decisions. An occasional patient who has been suffering with an undefined illness may actually feel relieved by bad news, which at least clarifies the problem. By exploring the meaning that the news has for the patient, the physician can better understand whether an affectively neutral exchange of information represents a coping style (intellectualization) that helps control and limit affect, or if in fact the news has little meaning for the patient. Other patients will go elsewhere to work through the emotional side of their responses (family, friends, other health professionals), preferring to keep the physician-patient relationship a more traditional biomedical exchange.

INFORMATIONAL NEEDS

Patients retrospectively report wanting information about the disease (prognosis, further tests, treatment options), the physicians' availability, and the impact of the disease on themselves, their families, and their careers. Whereas information in all of these domains is important, it must be tailored initially to the patient and perception of the problem, to direct patient questions, and to the patient's major cognitive distortions. Reconciling discrepancies between perceptions (HIV as an immediate death sentence) and the medical reality (likelihood of a significant latency period) is a vital early informing task. Since the patient's initial ability to integrate information may be markedly limited, the physician should give simple, focused bits of information, using language that the patient can understand. Both verbal and nonverbal responses to each piece of information should be observed, and the amount of information should depend on the patient's
continued active engagement. Information-laden physician colloquies unfortunately can alienate, distance, and control the patient without truly engaging.

Some of the information this patient needed at this initial visit included that (1) I would be her doctor and available to her; (2) the infection usually has a long latency period, and there are medical interventions to help control it (there is hope); (3) she is only contagious through blood or sexual contact; (4) she needs to tell her closest, most trusted supporting people, in this case her children; and (5) I would want to see her and any family she might choose in a few days. More complex information about HIV infection, unless specifically requested, would probably not have been retained at this initial visit.

The physician, too, has informational needs. The physician must assess and respond to the patient's immediate risks from the diagnosis, including the risk of suicide. There is epidemiological evidence of an increased incidence of suicide in patients with AIDS and other devastating illnesses, such as Huntington's chorea, renal failure, and cancer. The nurse's part in early HIV counseling, support, and suicide assessment for those who test positive for the virus is supported by several anecdotal reports of early suicide on hearing the diagnosis (Clinical Psychiatry News, October 1987:1). Defining suicide risk in those with newly diagnosed, serious medical problems includes an assessment of suicidal thoughts, feelings, and intentions in the context of the patient's previous mental health or substance abuse problems, prior suicide attempts, and social support. In a high-risk situation, immediate involvement of significant others, experienced counselors, social support programs, and even short-term hospitalization is essential. Suicide attempts immediately on hearing bad news before having time fully to integrate and understand the meaning directly reflect the hopelessness, isolation, and desperation many patients initially feel. Though these feelings were clearly present in this patient, she was able to assure me that she had no intention of committing suicide and that she was planning to inform her children and return to see me in 2 days. As with many patients, her despair and hopelessness lessened as she gathered her own health, learned more about the disease, and developed a plan. Yet, risk of suicide before this integration occurs remains high and should be anticipated and prevented if possible.

SUPPORT NEEDS

Being alone and isolated with a serious disease can be the source of severe suffering, and therefore should be limited as much as possible. In this patient's situation, my continued presence as her physician, as well as the strong suggestion that she confide in her children and close family members, allowed her family to support her more fully than ever. Deciding about how to work with her fundamentalist Christian church was more complex, since strong views had been expressed about how AIDS was God's response to sinful behavior. She decided it was too risky to share this information with her church, so she lost this means of support, which had been very important to her. She was informed about the availability of help from support groups and social agencies but was reluctant to share her grief with strangers. She did benefit from written materials about HIV infection. Supporters need to be mobilized but tailored to the individual so that he or she

The physician, too, may have support needs, particularly when the patient is having a strong, sustained response and/or when the patient's prognosis is grim. Physicians may also need advice about making difficult medical choices when the direction is still open, given the uncertain knowledge of the medical facts and the patient's preferences. These decisions are particularly difficult when there is a strong, long-standing physician-patient relationship and the physician is experiencing his or her own psychological and social support of trusted colleagues, physician support groups, and therapists can be extremely helpful for the physician who may suffer alone in this process.

DESIRED OUTCOMES OF EARLY MEETINGS

Minimize Aloneness and Isolation

This simple yet profound outcome underlies much of what needs to occur in the early meeting. Fully explain patient's emotional pain and cognitive responses, a contained presence, and mobilizing the patient's support are all part of this process. Social support is tailored to the individual patient, leaving the patient in control of who gets informed and involved. Physicians may also need to utilize social supports to work their own grief.

Achieve a Common Perception of the Problem

Understanding and exploring commonness and dis-set the stage for deeper understanding of the unique implications of the news. The physician's medical and emotional needs to be reconciled with the individualized perception and personal implications. The physician's understanding and exploring the patient's world can create a deep bond with the physician, help alleviate their isolation, and create the basis on which to build future normal relationships.

Address Basic Information Needs

Information must be tailored to the needs of the individual patient. It should be straightforward and translate the patient's situation and its implications. Information is given in small amounts, with opportunity for each patient to ask questions, rather than in a controlling soliloquy. The physician should listen and respond to the patient's questions. Complex emotional issues must be addressed over time.

Address Immediate Medical Risks, Including the Risk of Suicide

The risk of suicide on hearing about a devastating diagnosis is significant and should be assessed in each of the patient's visits. Sometimes medical situations will accentuate the risk. Patients may need to be reassured that they can cope with the bad news, but this can be allowed before making major medical decisions. When the patient is weaker, additional resources and considerations should be sought from knowledgeable people. When the patient is ambivalent, additional support and reassurance can make a tremendous difference in the patient's attitude and participation.

Respond to Immediate Discomforts

If anxiety, restlessness, or insomnia is persistent and overwhelming, then a short course of anxiolytic medication may be indicated. Similarly, physical pain should be treated...
ease are being explored. Though the physician should make every effort to lessen severe emotional and physical discomfort using medical measures and interpersonal skills, it should be kept in mind that (1) experiencing some emotional pain is necessary when coming to grips with bad news, and (2) if medications are to be used, they should be given in limited amounts because of the inability of the clinical situation and the risk of suicide. Discussion: that persists at subsequent meetings should be treated aggressively to minimize suffering as much as possible.

Ensure a Basic Plan for Follow-up

Ensuring a basic plan for follow-up makes the physician's continued presence concrete and alleviates the possibility of total alooseness with the problem. A plan for how to inform, involve, and answer questions of the patient's significant others should be developed. It is advisable, particularly if the patient is feeling overwhelmed and out of control, to prescribe some concrete tasks: telling specific people, seeing a consul-
tor, talking to individuals with similar problems, and/or writing down questions.

Anticipate What Has Not Been Talked About

If the initial meeting is all information and no affect, tell the patient he or she may have some strong feelings or reactions.

We are extremely grateful to the patient. Wiacek initial struggle is so gradually expressed in the transcript, for her generosity in sharing her experience. She is actually leading a normal life at this time, using her gift as the means of treatment. Her children have maintained all of her courage and resilience, though she has less choice now to share the news with her children. She has given many of us a lesson about courage and resilience.

References

5. Heim S. Words on anterior meningitis evidence in the clinical diag-

17. Quell TI. Recognizing and adjusting to barriers in doctor-patient commu-