A Request for Nondisclosure: Don’t Tell Mother

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Here’s the Case

Mrs. X was a 75-year-old woman who was admitted to the hospital with abdominal pain and severe depression. Her work-up revealed metastatic pancreatic cancer. Given her functional and nutritional status, her prognosis was less than 3 months. The patient had two daughters who were adamant that no one should tell their mom she has cancer. They understood that treatment was unlikely to prolong her life and wanted to take her home with hospice. You are unsure what to do—you feel like the patient has a right to know and yet her family is adamant that you cannot tell her because it will “kill her.”

Requests for nondisclosure, as reflected in the case, may cause clinicians considerable distress. Does the patient have a right to know the truth?1-4 What about informed consent and patient autonomy? Am I being asked to hide the truth or lie? Although the topic of nondisclosure raises legitimate ethical questions, we believe these cases are too often conceptualized as dilemmas in which one party must win and the other must lose: either the family is overridden and the patient told her diagnosis, or the physician’s conscience is violated and the patient is not told. A large literature lays out the arguments for and against disclosure in these cases. We think, however, there is a third way that often allows satisfaction of the patient, the family, and the physician’s concerns. This method depends on an understanding of the cultural factors that underlie the family and physician’s views and skillful use of negotiation techniques. In this article, we briefly review the literature on nondisclosure and provide some suggestions for handling requests similar to that posed in the case.

Historically, patient nondisclosure regarding serious, life-threatening, or terminal illness was the norm in virtually all societies.5 In 1965, Glaser and Strauss wrote, “[A]merican physicians ordinarily do not tell patients outright that death is probable or inevitable. . . .[F]amilies also tend to guard the secret. Family members sometimes may reveal it, but in our own study we never witnessed deliberate disclosure by a family member.”8 Only in this generation has there been a rapid shift in American medical values from nondisclosure to disclosure.7

In most other countries, both developed and developing, the primary recipient of bad news is the family.1,8-12 Although the issue of nondisclosure is being debated with increasing frequency in the world literature, the question is typically whether the patient should be told, in addition to the family.8,10,11,13,14 For example, as Uchitomi and Yamawaki11 point out, “In Japan, all family members are informed by physicians of the cancer patient’s diagnosis, condition, and therapeutic program, before the cancer patient is told the truth.” Although American clinicians may view requests for nondisclosure as a threatening departure from norms of clinical practice, from a global perspective, we are the outliers. It is important to recognize that cultures are not monoliths; significant differences in opinion exist within cultural groups regarding nondisclosure. Numerous studies have found that where family-oriented decision making dominates, many individuals both recognize the propriety of nondisclosure and yet personally wish to be involved in their own health care decisions.10,15-17 Statements like, “In our country the family decides, but as for me, I would like to be told what is going on and decide myself,” are common.

Communication and Requests for Nondisclosure

A number of studies have been performed regarding what patients,18-20 family members,21 and clinicians9,12,17,22,23 think ought to be communicated to patients regarding bad news such as a diagnosis of cancer, terminal status, or a poor prognosis. Only a handful of articles and book chapters24-28 give explicit suggestions regarding how best to handle requests for nondisclosure, and none of these is based on empirical outcomes. Thus, the approach suggested below is based on extrapolations from related work (sharing bad news, negotiation techniques, and cross-cultural communication strategies), and personal experience.29-40
A SUGGESTED STRATEGY FOR HANDLING A REQUEST FOR NONDISCLOSURE

Do Not Over-React

A common pitfall is to respond to the request with a categoric “We cannot do that. The patient must be told the truth.” Clinicians may over-react for a number of reasons. They may feel like they are being asked to act unethically. They cannot imagine not telling the patient her diagnosis of cancer. In addition, physicians may worry about their legal liability if the patient is not given sufficient information to make an informed decision. Finally, physicians may feel that their professional autonomy is trampled when nonclinicians tell them what they should do.41

By over-reacting, the physician loses the opportunity to learn why the family is asking that their loved one not be told the diagnosis. Rather than framing the conversation as an attempt to respect all parties’ values, this response frames the conversation as zero-sum argument in which one side must win and the other must lose. The family may view the response as a moral criticism of how they are caring for their loved one, and in turn, respond by escalating the conflict.

Thus, it may help to take a deep breath before responding. This is a difficult topic about which both clinicians and families likely have strong opinions. Taking the time to acknowledge, at least to oneself, that this is a difficult conversation, allows the clinician the space to keep from becoming overwhelmed by emotions.

Attempt to Understand the Family’s Viewpoint

The clinician is encouraged to step back and try to understand the family’s request. Before sharing your concerns, try to understand why the family members are making this request. This is respectful and is likely to decrease their anxiety. Moreover, the clinician may gain valuable information that might alter how a solution could be negotiated. “Tell me about your concerns” may help start this conversation.

Requests for nondisclosure can better be understood by considering the requester’s explanatory model of illness.42,43 A person’s explanatory model of illness relays a story about what the individual thinks has happened and will happen, how the illness ought to be managed, and by whom. Table 1 outlines questions that might be asked in exploring the requester’s explanatory model.

In some cases, discussion may reveal that the patient had clearly stated that he or she did not want to be informed of bad news and preferred to defer to family members for decision making. In other cases, the family may be basking their request on how similar situations were handled in the past by the family and the patient. In many cases, however, family beliefs are based more on general cultural expectations than explicit discussions with the patient or a particular experience.

Regardless, family members commonly advocate for nondisclosure because they believe their duty is to relieve the sick person of the burden of worry, loss of hope, and responsibility for difficult decisions. This sense of duty arises from a moral stance called role obligation, in which the person believes that the greatest good will result if he or she is “true” to particular role—in this case that of family protector.44

Be Flexible

The family’s reasons for nondisclosure may cause the clinician to re-evaluate his or her position. For example, if the patient had previously said she did not want to be told if she has cancer (as is common in many cultures), the clinician may reconsider concerns about the patient’s autonomy. As Orona et al45 have pointed out, to defer autonomy can be an act of autonomy. In making their requests, family members often have not considered the practicalities of the modern medical world.46 For example, if a request is made to inform a patient with cancer that he or she has an infection being treated with antibiotics, families generally have not considered how to explain certain adverse effects such as hair loss or the necessity of treatment in the oncology clinic. In this case, where a hospice admission was sought, it might be difficult for the family to explain hospice’s involvement. After understanding the family’s view, you can offer to think through with them the implications of their reasoning. “I wonder if you have thought about some of the practical issues associated with not telling your mother about her diagnosis. Can I mention some of my concerns?”

Respond Empathically to the Family’s Distress

In this case, the daughters’ request was a sign of distress. They had just been told that their mother is dying and were trying to protect their mother from hearing the same bad news. In our experience, emotions are central to these disputes. Given that this is a topic both parties care deeply about, it is not surprising that issues of pride, respect, and self-esteem surface. People become sensitive and quick to find flaws in the other person to strengthen their position. Feelings of anger, frustration, or inadequacy may arise. For the family, the conversation about telling their loved one about her diagnosis is tied to their feelings about her illness.

Empathically attending to the family’s emotions is important. Establishing an empathic connection with the requesting person will foster a positive relationship, building a foundation for subsequent discussion and negotiation. In addition, when people are overwhelmed by their emotions, they have trouble listening. Empathic responses often decrease distress, allowing people to more clearly hear the cognitive information. Finally, by responding empathically to their emotions and helping them with their sadness, the clinician also may show that he or she can help their mother deal with her sadness. An example of an empathic response might be, “I understand this must be a difficult time for you and your family.” Or “I see how worried you are about your mom.”

Table 1. Example of Explanatory Model Questions in Nondisclosure

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<td>Tell me more about your loved one. What is his or her role in the family and how would he or she normally handle things?</td>
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<td>Is he or she the person who is normally in charge of things, or does he or she tend to defer to others and follow their wishes?</td>
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<td>What is your understanding of your loved-one’s illness?</td>
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<td>Why are you making this request?</td>
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<td>What do you think would happen if your loved-one were told of his or her condition?</td>
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<td>Who do you believe should be the decision maker, if not the patient, and why?</td>
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<td>If your loved-one asks about his or her condition, what should be said?</td>
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<td>What role do you see us clinicians playing in this?</td>
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<tr>
<td>Do you foresee or worry about any problems if we proceeded in this way?</td>
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Talk to the Family About What the Patient Would Want

It is common in many cultures to simply assume that the patient would share the explanatory model of the loved-one making the request for nondisclosure. Available evidence suggests that in many cases, this is not so; the patient may really want to know. Of course, a big problem with nondisclosure is that it inhibits sharing of differences of opinion. Thus, in many cases, requesters will simply assume that the patient shares their viewpoint. The clinician might ask family members questions like, “Have you ever discussed how to deal with this sort of problem in the past,” or “How has he or she dealt with similar situations in the past,” when the patient was in a caregiver role. However, extrapolation from prior patient caregiving behavior, in which the patient might have concealed truth from another family member, must be interpreted with caution. In many cultures proper behavior, driven by role obligation, is role-specific.47 For many people there is no inconsistency between wanting to know the truth for oneself as a patient and wanting to conceal truth as a family member. In both cases the person may be motivated by a role obligation first and foremost to protect the other. Just as a family member might worry about the burden of decision making imposed on the patient, the patient might similarly worry about imposing a burden on the family.

Where family members presume patient agreement with nondisclosure, the clinician may suggest the possibility that the patient might have a different opinion. “I wonder how we would know if your mother did want to know more about her illness?”

State Your Views As Your Views

It is important when sharing your view to be nonconfrontational. This is one of the reasons it is usually best to wait until you clearly understand the family members’ views and have responded empathically to their distress. In expressing your views, it is important to make it clear that they are your views rather than the only views. This is typically done by speaking in the first person (I believe or I think) rather than universally (the patient has a right); and stressing the common ground shared with the family (“I think we are both struggling with how to do the best for your mom”). Thus, for example, a clinician may express worry that the he or she might fail to uphold the obligation to inform the patient (“As a doctor, I feel I have an obligation to my patients to let them know what is wrong with them”). When differences are found, they should be expressed in as clear and positive a light as possible.39 Table 2 outlines some examples of skilled and less skilled ways to express clinical values.

Propose a Negotiated Approach

For the patient with decision-making capacity, the challenge is to figure out what the patient wants without providing disclosure in the process. The clinician may propose talking with the patient regarding his or her wishes. As a part of this negotiation, certain ground rules and possible outcomes should be considered in advance. The clinician should be explicit that the goal is not to talk the patient into anything: “I am fine with you (the family member) being the decision maker, if that is what she wants. I just want to confirm that, so we are doing what she wants.” Role-playing with the family what you would say to the patient may be an effective way to reassure the family that you are trying to respect their loved one’s wishes. The clinician must communicate verbally and nonverbally his or her comfort with the patient deferring to the family, if indeed that is the patient’s wish. In fact, with the family’s permission, it may be appropriate to tell the patient about the family’s concerns. For example, “Your daughters are really concerned that you get anxious and overwhelmed when the doctors give you information about your health. Knowing that, I wanted to talk to you about how much information you would like to get.” How the above is communicated is every bit as important as what is said.

The clinician may wish to negotiate whether to talk with the patient separately or together with the family. There is no general consensus on this. Theoretical arguments in favor of both approaches can be advocated. Some families want to be there to make sure the choices are presented neutrally, whereas other families find it too emotionally stressful. Patients may also vary in their opinion: some families make most of the decisions. Although these are different approaches, I think everybody is trying to figure out how to provide the best of care.

Table 2. Communicating Clinician Values about Nondisclosure

<table>
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<th>Less Skilled</th>
<th>More Skilled</th>
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<td>The patient has a right to make her own decisions</td>
<td>I want to make sure your mother is involved to the degree she wishes. If she wishes to defer to you, that is fine with me.</td>
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<tr>
<td>You want me to lie to the patient? I can’t do that!</td>
<td>I appreciate your desire to protect your mother from undue distress and harm. I share that desire. It also is important for me to be truthful. Thus, if she asks me to tell the truth, I must do so.</td>
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<tr>
<td>This is the United States. In this country, the patient, not the family makes the decisions.</td>
<td>In the United States, most people believe a clear-thinking patient should make her own decisions. I appreciate that in many places families make most of the decisions. Although these are different approaches, I think everybody is trying to figure out how to provide the best of care.</td>
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<tr>
<td>Even if we went along with this, we cannot control everybody in this hospital. Somebody is bound to say something. For all we know, she may already know what is wrong with her.</td>
<td>Even if a decision is made not to disclose her diagnosis, you need to know that a staff person might inadvertently say something, despite our best efforts. Your mother is a smart woman. Do you think there is a possibility that she may already know but does not feel free to speak, because she is worried about upsetting you?</td>
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<td>As a physician, I need to make sure we get informed consent from the patient before we do the procedure</td>
<td>Just as you have an obligation to your mother as a family member, so do I have an obligation as her physician. My obligation is to make sure she gets the best possible care, and is involved in decision making to the degree she wishes.</td>
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In conclusion, requests for nondisclosure are not rare. Using communication and negotiation skills as outlined above, we believe difficulties arising from such requests can be resolved successfully in the vast majority of cases. It is hoped that future research will be conducted on these and related communication skills, both to examine their effectiveness and refine skill training.

AUTHORS’ DISCLOSURES OF POTENTIAL CONFLICTS OF INTEREST

The author(s) indicated no potential conflicts of interest.

REFERENCES


Table 3. Summary Steps in Addressing Requests for Nondisclosure

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<th>Step</th>
<th>Elaboration</th>
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<tr>
<td>Take a deep breath</td>
<td>Ensure availability of an appropriate place and adequate time to address the request. Do not overreact.</td>
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<td>Find out their story</td>
<td>Explore their explanatory model. Why are they making this request?</td>
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<td>Respond empathetically to their distress</td>
<td>“I respect that you are concerned for your loved-one. This must be a difficult time for all of you.” “I appreciate and share your concern. None of us want her to lose hope. We all want what is best for her.”</td>
</tr>
<tr>
<td>Talk to the family about what the patient would want</td>
<td>“I wonder how your mom would know if your mom did want to know more about her illness?”</td>
</tr>
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<td>Find out how the patient normally functions inside the family unit. Is this person the one who is always in charge of everything, and always has to be the leader, or does this person defer to others?</td>
<td>“Tell me how your mom normally handles situations? Is she the one in charge, or does someone else make the decisions at home?”</td>
</tr>
<tr>
<td>Explain your position and the explanatory model favoring disclosure</td>
<td>See suggestions in Table 1</td>
</tr>
<tr>
<td>Negotiate your approach to talking with the patient</td>
<td>Explain the importance of truthfulness for you. Negotiate whether to discuss with or without family present. Negotiate how you will respond if the patient asks to be told the truth.</td>
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Talking With the Patient About His or Her Desire For Information: Asking For the Patient’s View and Wishes

In talking with the patient, it is best to begin with an open-ended question such as, “What is your understanding of your situation or medical condition (some patients may not even know they are ill)?” The clinician should not be surprised to learn that the patient already knows the diagnosis, but has been “playing along,” as if this was not known: this is defined as a process term, closed awareness, by Glaser and Strauss.48 Of course, the patient really may not know or just suspect. Some clinicians may wish to present the question about disclosure as neutrally as possible: “Some patients want to be told directly about their illnesses and others would prefer for the family (or a specific individual) to be in charge. What do you want in this regard?” Others may slant the question more directly in favor of the request for nondisclosure: “You daughters told me that in your family, details and decisions regarding your illness and care should be handled by them. That is fine with me, if this is what you wish.” If the patient states that she wants to know and to be in charge, this should then be pursued, as discussed.

One may object to this extended negotiation, arguing that going through it is “as good as telling the patient the diagnosis.” This view, however, conflates open and closed awareness. The patient may know her diagnosis and also want to be respectful of the family culture that such things are not discussed openly. This model allows for that aspect.

In addition, patients have an amazing ability to hear what they want and need to hear. Thus, in our experience, a patient who does not wish and need to hear. Therefore, in our experience, a patient who does not want to “know” is unlikely to take this conversation as meaning there is “bad news.” Table 3 summarizes suggested steps in addressing requests for nondisclosure.

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Non-Disclosure Agreements probably don’t make sense for start-ups trying to raise funding from venture capital investors, as most venture capitalists will refuse to sign such agreements. Mutual vs. Non-Mutual NDAs. Non-Disclosure Agreements come in two basic formats: a mutual agreement or a one-sided agreement. The one-sided agreement is when you are contemplating that only one side will be sharing confidential information with the other side. The mutual NDA form is for situations where each side may potentially share confidential information. Although there is always some appeal to using a mutual agreement for nondisclosure, as reflected in the case, may cause clinicians considerable distress. Does not the patient have a right to know the truth? What about informed consent and patient autonomy? They had just been told that their mother is dying and were trying to protect their mother from hearing the same bad news. In our experience, emotions are central to these disputes. Given that this is a topic both parties care deeply about, it is not surprising that issues of pride, respect, and self-esteem surface. These conversations, nondisclosure requests from the families, and the use of families can be successfully resolved in the vast majority of cases, said Dr. Arnold. Although clinicians in the U.S. often view requests for nondisclosure as contrary to common medical ethics and norms of clinical practice, many families and patients, nonetheless, do not want bad news disclosed. Family members, who may have the patient’s best interests at heart, may believe that the patient would give up hope if given the news. These requests put physicians in difficult situations in which they feel as though the patient has a right to know, yet the family is adamant that the patient not be told,” said Dr. Arnold.