Mrs. K. M., a 37-year-old ultra-orthodox Jewish mother of two small children, presents with metastatic pancreatic cancer with extensive liver metastases. She is weak and cachectic. Given the very advanced disease and her poor performance status at presentation, the outlook is poor and the likelihood of substantial benefit from chemotherapy is small. The family, who were told of her diagnosis by the diagnosing surgeon, request that you not tell her how serious her condition is. They explain that in their culture any information should be given to her husband, and that he and his rabbi will decide what is best for her to know.

At times when her family has not been present, the patient has repeatedly remarked to the junior resident that she wants to be told what is happening to her. You, the attending of record, sit by her bedside and take her hand. She turns on her pillow, looks you in the eye, squeezes your hand, and says, “I want to live! I need to see my children grow up! I need you to give me hope! I am the sick one here but I feel like no one is talking to ME.”

Questions abound:
• Are you going to tell her what is going on despite the explicit request of her family?
• How much will you tell her about the grim prognosis or the low likelihood of benefit and the potential for harm from treatment?
• Does her plea for hope demand that you hold back on disclosing the full scope of the impending tragedy?
• Without all of the information, how can she possibly make an informed decision about whether to receive what will probably be ineffectual and possibly harmful chemotherapy?

Oncologists caring for patients with advanced cancer typically need to engage in repeated, emotionally challenging conversations with patients and their families. This is one of the most difficult aspects of the oncologist's role.[1,2]

Patients are dealing with the emotional impact of a life-threatening illness and with decisions regarding treatments that are often complex and that may offer limited likelihood of benefit, while at the same time trying to strike a balance between maintaining hope and having realistic and achievable goals.[3-5] Interactions between patient and oncologist occur in the context of patient preferences, family, and culture, all of which profoundly influence the discussions. These factors influence the amount of information patients want, how they want to receive that information, and ultimately, how they make decisions regarding their medical care. How these discussions are carried out is a matter of profound consequence for the emotional well-being of patients and their families.[6,7]

Several aspects of communication between oncologists and their patients remain contentious:
• Autonomy: To what degree must physicians observe the principle of full disclosure in order to ensure true autonomy and informed decision making on the part of the patient?
• Culture: In caring for patients from different cultures, how should the physician respond to requests of family members who claim that in their culture decision making should be left to the family rather than to the patient?
• Paternalism: How does one balance the need for information with the concern that some patients may be harmed by physicians' honoring requests for either too much or too little information? When should the physician invoke the “therapeutic privilege” of paternalistically overriding a patient request or not seeking the patient's opinion?

Despite advice from philosophers, sociologists, psychologists, and communication experts, these issues continue to plague and often confuse individual oncologists as they confront challenging and sometimes tragic situations.[1,2,8] This article outlines a nuanced approach to the concepts of
autonomy, culture, and paternalism, as these relate to the sorts of issues raised in the questions above. The approach is contextualized with important sociological observations that can provide further help to clinicians as they address the questions that arise in daily practice; these observations also suggest some pragmatic solutions.

**Autonomy**

*To what degree must physicians observe full disclosure in order to ensure true autonomy and informed decision making on the part of the patient?*

Patient autonomy is generally understood to imply that physicians ought to disclose as much information as desired by the patient to facilitate participation in decision making to the degree preferred by the patient.[9] Disclosure, in this context, refers to the imparting of information necessary to make informed decisions about ongoing care. The key types of information disclosed include information regarding the diagnosis, the extent of disease, the range of therapeutic options available, the likelihood of benefit or harm from each of the treatment options, the potential severity of any possible adverse effects, and the anticipated extent of benefit.

What is often overlooked, however, is that autonomy has a spectrum of expressions encompassing isolated autonomy, relational autonomy, and voluntary diminished autonomy.

- **Isolated autonomy:** Common ethical discourse often involves a very narrow definition of autonomy—that of isolated autonomy, which relates to a concept of self-interest totally detached from relational or other considerations.[10]

- **Relational autonomy:** Most persons live in cultural and familial contexts involving obligations, duties, reciprocal relationships, and interdependence.[11,13] More often than not, patients voluntarily consider the impact of their decisions on valued relationships and seek the counsel of family members or other significant stakeholders in their lives in the process of making decisions. Cultural and interpersonal factors may influence the degree to which patients incorporate these considerations into their deliberative processes. When the relationships involved are not coerced, this is a valid expression of autonomy.[11]

- **Voluntary diminished autonomy:** Some patients have valid concerns that they may be harmed by excessively candid diagnostic or prognostic information or by the burden of decision making. They may not want to know the exact nature of their disease, its extent, or the details of their likely prognosis.[14-17] To protect their perceived self-interest, they may request that some issues remain unaddressed, undisclosed, or vague. Respecting this sort of request has been called “necessary collusion,”[14] but it is better described as voluntary diminished autonomy. Although the decision to request limited information is autonomous, having less information renders the patient less able to make informed decisions. Indeed, these requests often go hand in hand with a request that the decision making be guided by the physician's recommendations (ie, “I will agree with whatever you feel is best for me”), or a request to delegate the decision making to another person,[18-22] often a family member, religious leader, or the treating physician (ie, “I want someone else to make the decision for me”).

Another variation on voluntary diminished autonomy is the patient who does not see it as his or her role to make medical decisions.[20,22] He or she may feel, for personal or cultural reasons, that the decision making should be the responsibility of some other person, be it a relative, the treating physician, a communal leader, or a religious authority.

Respect for autonomy, therefore, requires a nuanced understanding of the sort of autonomy that the patient desires—and this does not always require a process of “full disclosure.” Indeed, excessive disclosure or candor in situations in which it is not desired or requested may sometimes be considered an “assault of truth.”

Voluntary diminished autonomy has important implications for the consent process. A patient who chooses not to receive all of the relevant information cannot give informed consent to treatment, and the usual approach of asking the patient to sign an “informed consent” document is inappropriate in such a setting. In a situation such as this, an assent form should include the following elements: TABLE 1
Examples of Questions That Can Facilitate an Understanding of Patient Preferences Regarding Disclosure of Information

- A statement that the patient has been offered information about his or her condition and the treatment options.
- Confirmation that the patient has been provided all of the information that he or she wanted to receive about his/her condition, treatment options, the likelihood of benefit, and the risks involved.
- Confirmation that the patient has entrusted the informed decision making to a nominated person who has been fully informed of the likelihood of benefit, the potential risks of harm and burden, and alternate therapeutic options. That person may be asked to either make the decision on behalf of the patient, or to recommend the treatment to the patient for his/her approval.

When informed treatment decision making is delegated, it is prudent that the surrogate decision-maker confirm that there has been an informed decision-making process based on full disclosure of potential benefits, risks, and alternatives.

Some useful communication strategies for eliciting patient preferences regarding disclosure of information are presented in Table 1.

Culture

In caring for patients from different cultures, how should the physician respond to requests of family members who claim in their culture decision making should be left with the family rather than with the patient?

In recent years there has been substantial focus on the impact of culture on the communication process.[23,24] It is often suggested (somewhat reductively) that the world can be divided into ethical cultures that are either autonomy-based (found mainly in North America, northern Europe, and Australasia) or family-centered (the dominant type in Mediterranean, Eastern European, Asian, and traditional societies).[25] In this simplified model, autonomy-based ethical cultures have a strong focus on the individual patient's decision making and full disclosure to facilitate informed decision making. In contrast, family-centered ethical cultures are characterized as protecting patients from bad news in difficult situations.

Advocates of the view that the world can be divided up into two types of ethical cultures hold that the strong emphasis on autonomy that has become a dominant ethical theme in Western cultures may not be appropriate for non-Western societies,[26-31] and some claim that insistence on an autonomy-based approach may represent a disrespectful, insensitive, inappropriate, and potentially harmful form of "cultural imperialism."[27-31] This reductive view lacks nuance and runs counter to the evidence. There is substantial sociological and ethnographic data indicating that it represents an oversimplification of both Western and non-Western cultures. Adherence to an approach based on such a view may lead to excessively candid disclosure of information to some patients in Western countries who may personally prefer a lesser degree of disclosure of "bad news"—or to the unrequested withholding of information from patients in non-Western cultures who actually want more information and who want to be more involved in the decision making about their fate and well-being.

Culture is a complex concept that consists of traditions, beliefs, values, norms, symbols, and
meanings that are shared, to varying degrees, by members of a community. It refers to shared realities and norms that constitute the learned systems of meaning for a particular community.[32]

Culture influences the perceived scope and significance of obligations, duties, and interdependence with family; the perceived role of the patient in the decision-making process relative to that of other stakeholders in medical decision making; and the perceived likelihood that harm will arise from patient involvement in the decision-making process.[32]

It is critical to keep in mind that membership in a culture is not a social contract, and that persons within a cultural group may adhere to some norms while selectively rejecting others.[33,34] Thus, one of the outstanding characteristics of any cultural group is the existence of heterogeneity.

Neither cultural origin nor affiliation accurately predicts patient preferences regarding information transfer or decision making. Data suggest that there is substantial heterogeneity of preferences and that these cannot be predicted for any given individual on the basis of geography, culture, age, race, sex, religion, or education level.[35-62] Furthermore, there is often profound dissonance between family members' perception of a patient's preferences and the patient's actual preferences.[56,62-67] Thus, one cannot assume that communication preferences are culturally implicit[25] or that they can be reliably ascertained from family members; rather, they need to be explored individually with each patient.

**TABLE 2**

An Approach to Talking to Family Members When They Have Made a Request That Information Not be Given to Their Loved One

Based on the above data, there is a very broad consensus of ethical,[25,68,69] medical,[24,39,47,70-72] psychological,[73] legal,[74], and anthropological[33] perspectives that physicians should ask patients about their individual preferences and act in accordance with patients' wishes unless there are compelling contraindications derived from concerns for harm.

It is helpful to ask patients about their information preferences at the same time that they receive information about the diagnostic or invasive procedure that they are about to undergo. We recommend offering patients a range of options: explain the results to me, explain the results to me with my family members, explain them first to my family and then to me, or tell the family first and let them decide what I should be told. This approach recognizes and ensures that authentic patient preferences are obtained and respected, avoids cultural stereotyping and unauthorized breaches of confidentiality, reduces the potential for a physician/family collusion to withhold desired information, and reduces the potential for conflict with family members by focusing on respect for known, documented patient preferences.

When a conflict does arise with family members who want to prevent discussion with the patient, a strategic approach such as that presented in Table 2 is often helpful.

**Paternalism**

*How does one balance the patient's need for information with the concern that some patients may be harmed by their request for either too much or too little information?*

*When should the physician invoke the “therapeutic privilege” of paternalistically overriding a patient request or not seeking the patient's opinion?*

If the clinician is concerned that harm may ensue from a patient's preferences—either a request not to receive important information (with the potential for poor decisions based on incomplete information regarding the likelihood of risks or the limitations of benefits) or a request for too much information (with the potential for severe psychological distress)—the physician has an obligation to discuss these concerns and to attempt to persuade the patient to change his or her request.[75,76]
Attempts at persuasion are a legitimate, nonpaternalistic expression of respect for a patient's well-being.\[77\]

A line is crossed when one chooses to overrule the preferences of the patient or not even to evaluate what the patient's preferences are. The justification for overruling a patient's preferences—the claim that this is ethical—is usually explained in terms of “paternalism” (acting like a parent who makes decisions to protect a child). Paternalism is defined as a situation in which a clinician interferes with a person's autonomous decision (either by overriding it or by not inquiring about the person’s preferences) in order to avoid harm and to promote the authentic welfare, happiness, needs, interests, or values of the person.\[77,78\]

Nondisclosure and paternalism are often confused, or the terms are used incorrectly. Nondisclosure may, or may not, be paternalistic. Nondisclosure at the request of the patient is not paternalistic since it does not contradict the patient's wishes; in contrast, fully disclosing a prognosis to a patient who does not want the information is paternalistic.

**Soft paternalism**

Physicians sometimes act against the preferences of a patient out of concern that the patient’s expressed preferences may be inauthentic. Physicians may have good reasons to doubt the authenticity of the patient’s expressed preferences when they suspect that the patient may not be competent (usually by virtue of either immaturity or mental illness) or when there is compelling evidence that the patient's decision has been coerced.\[79,80\] Acting against inauthentic preferences is called “soft paternalism.”\[78,81\] Judgments in these situations involve subjective deliberations. This is true for determinations of competence (such as in the case of a mature minor) and especially for judgments that coercion has occurred.

When a patient's decision seems to be unduly influenced by the opinion of family members, it is often difficult to distinguish between legitimate persuasion by family members who have appealed to duty or reciprocity, and coercion (where threat is a defining feature).\[80\] In some relationships there may be an implicit or explicit threat of adverse emotional or relational consequences for noncompliance with the requests of relatives.

Consider, for example, what the implications would be if, in the introductory vignette about Mrs. K. M., that after a conversation with her husband in which he said “If you don't trust me to do the talking to the doctors, I will feel as if you have betrayed me,” she asks to cancel the scheduled meeting with the attending. For the care team, it would not be clear whether this change of heart represented an expression of filial responsibility or a response to the threat that she would be held responsible for her husband's sense of betrayal if she didn't comply with his wishes. When such concerns exist, it is useful and important to explore the circumstances of the decision with the patient to ensure that the decision does indeed reflect his or her current preferences.

**Hard paternalism**

In order to attain the best possible outcome for their patients who are competent and not coerced, sometimes physicians either do not seek their opinions or preferences, or they actively contravene patients' expressed preferences.\[78,81\] Hard paternalism aims to serve patients' interests by reducing potential harms or promoting their interests better than the decisions, or potential decisions, of the patients themselves.

The physician's privilege to act against a patient's authentic preferences (therapeutic privilege) is unique among the professions; it is based on four considerations\[82,83\]:

- **Stewardship**: this refers to the duty of physicians to intervene in a precautionary manner to prevent harm.
- **The asymmetry of knowledge and judgment between the physician and the patient.**
- **Presumed physician integrity.**
- **The beneficent protection and promotion of authentic patient interests.**

Either not asking patients about their preferences or acting against them can be a major, and, in some countries, a potentially sanctionable offense unless there is compelling and coherent justification. A potential justification should meet five criteria \[81\]:

1. The patient must be at risk of a significant preventable harm.
2. The paternalistic action will probably prevent that harm.
3. The expected benefits outweigh the risks to the patient.
4. Persuasion has failed, and there is no reasonable alternative to overriding the patient's autonomy.
5. The approach that is taken is the least restrictive of the patient's autonomy.
Regarding paternalistic nondisclosure of diagnosis or prognosis: partial truths or partial concealment or generalities about the disease or its anticipated outcome are less restrictive of the patient's autonomy than untruths, avoidance, or concealment. In practice, hard paternalism is relatively common[84-91] and probably more common than can be justified on the basis of the accepted criteria. Empiric data indicate that oncologists frequently choose not to disclose the limited likelihood or scope of benefits of proposed antitumor therapies in the setting of advanced cancer,[84-91] that many patients often receive less information than they want,[39,51,92] and that some patients are exposed to more information than they have requested.[39,93-97]

Different physicians have different thresholds for invoking the therapeutic privilege. Several factors may influence that threshold:

1. The perceived importance of the obligation of precautionary intervention may be influenced by the expectations of the patient, demands or expectations of family members, the prevailing culture, local professional norms, or perceived professional role expectations. For example, in some settings cultural norms may support nonconfrontational and avoidance behaviors, and in some cultures authority figures are not expected to negotiate terms with persons in the relationship who are of lesser authority.[32]

2. The appraisal of the likelihood of harm or of the severity of harm may be influenced by the skill of the physician (or lack thereof), evidence, experience, hearsay, or culturally relevant legend or metaphysical beliefs.[98,99] In some instances, cultural factors may amplify the perceived risk and likelihood of potential harms. This has been amply described in the care of Navajo patients, whose metaphysical belief system incorporates the notion that thoughts and fears can influence outcomes.[98,99]

3. The appraisal of the harm caused by undermining patient autonomy may be influenced by cultural factors in cultures that place less emphasis on respecting individual preferences and more on the protection of the vulnerable.

4. A physician may or may not have familiarity with, skill in, and availability for influencing a patient's preferences through other approaches, such as persuasion, values exploration, suggestion, or use of second opinions.[85]

5. Physicians who lack preparedness and time for complex communication tasks may avoid them by taking unilateral paternalistic approaches such as not exploring patient preferences. This is particularly true for physicians who lack training in dealing with the emotional aspects of patient care, suffer from burnout, feel overburdened, lack time to devote to complex dialogues, or lack training and/or experience in dealing with end-of-life–related tasks.[85]

The therapeutic privilege either not to seek, or to contradict, patient preferences, is easily abused,[100,101] and it is incumbent on the mindful clinician to be prepared for challenging communication tasks and to develop the skills necessary to navigate them. These skills include empathic communication, disclosure of diagnostic and prognostic information in a stepwise and sensitive manner, ways of minimizing emotional responses, and approaches for coping with such responses when they do emerge.[1,102-104].

Conclusions

Difficult dialogues with patients facing life-changing decisions are an intrinsic part of oncologic practice and a major source of stress. Having a nuanced approach to the concepts of autonomy, paternalism, and culture helps in addressing difficult situations that arise around the issues of disclosure and decision making. Clinicians ought to be familiar with the concepts of relational autonomy and voluntary diminished autonomy, and with the implications of such concepts for care and especially for the consent process. When there is concern that a request for either too little or too much information may result in patient harm, and when the patient persists in the request despite efforts to persuade him or her of its unwiseness, in limited circumstances, and with substantial circumspection, either soft or hard paternalism may sometimes be justified. Ethical literacy regarding the issues involved in difficult communication problems is an important competency for medical oncologists and must be part of all training programs.

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