Withholding Information from Patients — When Less Is More
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As clinicians who strongly value truth telling and active patient involvement in medical decision making,1 we have lately been reflecting on the circumstances in which physicians consciously (and sometimes unconsciously) withhold from patients information about their conditions, treatments, and outcomes. The ethical principle of autonomy would suggest that patients should always be fully informed, not only so that they can make the best possible decisions, but also because information helps them to make sense of and cope with illness. However, since information can sometimes increase patients’ cognitive and emotional burden and lead to greater confusion rather than clarity, the right to autonomy must be balanced with the ethical obligations to do good for patients (beneficence) and not to harm them (nonmaleficence). Physicians routinely make judgments about whether time taken to provide information will detract from other important tasks, such as making decisions or promoting adherence to treatment regimens.

Clinicians and ethicists are generally comfortable with the idea of withholding information in several types of situations. If a patient lacks the cognitive capacity to understand the information, then it should be provided to a surrogate. If there is a need to intervene urgently (e.g., in the case of a ruptured aortic aneurysm), the potential benefits of early intervention often outweigh the potential harms of incomplete or delayed disclosure. If patients explicitly or implicitly (e.g., through silence or repeated changing of the subject) choose not to receive important clinical information, then a health care proxy should be kept informed while the reasoning behind patients’ refusal of information is explored. But decisions to withhold information should be reconsidered if a patient asks directly for information, or if the perspectives of the patient and his or her family about the clinical situation appear to be discordant.

Still, there remains a gray zone — situations in which physicians (consciously or unconsciously) withhold information from patients who have the capacity to understand and have not articulated a desire not to be informed. In these situations, choices about providing or withholding information should be made in such a way as to maximize benefit and minimize psychological and cognitive and emotional burdens. When considering whether the information will be of any significant benefit to the patient, clinicians should assess both instrumental benefits — help in making decisions, in providing meaningful options, and in obtaining access to resources — and emotional or relational benefits — helping the patient to cope, find meaning, defuse shame or blame, and build trust.

The consideration of potential burdens of information is more complex. For example, cognitive overload from too much information may impair rather than facilitate understanding and decision making, especially when patients and families are under considerable emotional and physical duress. A recitation of an exhaustive litany of improbable side effects of a medication, for example, can not only obscure more relevant information but also distract patients and physicians from practical discussions about the purpose and logistics of treatment. Detailed discussions of incidental findings — a benign liver cyst, say, noted on the computed tomographic scan of a patient with a suspicious lung nodule — can derail exploration of the complexities of a serious illness and the relevant treatment options. Informing a patient with panic disorder about borderline prolongation of his QT interval might reinforce his fears about cardiac disorders and distract from educating him about his panic disorder and initiating treatment.

The emotional nature of some information that is irrelevant to prognosis or treatment choices may result in unnecessary distress. For example, in a child with leukemia, the finding of a single blast cell on a routine follow-up blood count may have no prognostic significance and will not affect decision making, yet the information may be very distressing to parents.

Providing every detail of clinical information also takes time and may crowd out more important discussions. Time taken to explain to a hospice patient that she now has five rather than three pulmonary metastases might be better used to discuss how to relieve her symptoms or how her family is coping. If a screening-mammography report contains language suggesting that the im-
age was technically imperfect yet good enough not to warrant repeat imaging before the next scheduled screening, the time spent relaying that information might be better spent reinforcing other healthy behaviors.

Finally, clinicians should consider how the information might enhance or reduce patients' autonomy. If patients find information clarifying or empowering, they are better able to make decisions that are consistent with their values. However, more information is not always better. Dumping all available information on patients can be overwhelming and may paradoxically undermine their ability to choose wisely. Furthermore, patients' ability to acquire and use information and fully participate in their care does not depend solely on how much information they receive — it also depends on the nature of their relationships with their clinicians, their families, and others. If patients distrust their physicians, they tend to seek more information. If patients are left alone to sort out complex information, they may feel abandoned and less able to exercise control. The ideal goal may be "autonomy-in-relation," which entails collaboration among patients, their loved ones, and clinicians in seeking, interpreting, contextualizing, and acting on information.

Physicians regularly make tacit judgments about the amount of information that patients can reasonably assimilate, how to interpret and contextualize it, how it will affect patients' and families' ability to cope with the illness and make informed decisions, and how to avoid frightening or overwhelming patients with details. These judgments ideally take into account physicians' knowledge of the patient as a person, including the patient's cognitive capacity, level of literacy and numeracy, values, and desire for detailed medical information.

However, physicians need to guard against conscious or unconscious bias in their exercise of "clinical judgment" regarding withholding possibly relevant clinical information. Though most would disavow any prejudice, physicians, like all humans, exhibit bias in their behavior. For example, physicians tend to provide black patients with less information about their illnesses than they provide to white patients, even when educational level and socioeconomic status are taken into account. In time-pressured health care environments, clinical judgment may be used as a rationale for withholding information in order to avoid time-consuming or burdensome aspects of care. Our current financial incentives generally favor interventions and discourage informative conversations about the limits of treatments. Furthermore, some physicians might withhold information — omitting mention of alternative treatments or controversial aspects of care — simply to avoid conflict with potentially contentious patients or families.

Clinicians' everyday decisions about how much detail to share with patients require self-awareness and honesty. In our view, clinicians should withhold information that is likely to overwhelm and distress patients if they having the information would provide no obvious benefit and they don't ask for it; information overload — especially if the information is not clinically relevant — may render more important discussions impossible. There may be situations in which it is even appropriate to withhold information of potential significance (or to delay its disclosure), but they are exceptions. We propose some simple rules: If the patient asks, the clinician should tell. If the clinician is anxious about what would happen if a patient discovers that information has been withheld, then the decision to withhold should be reconsidered. Clinicians should scrutinize their tacit judgments by routinely asking themselves questions such as "What would a trusted peer say?" "Am I feeling uncomfortable?" or "Am I assuming that the patient's values are the same as mine?" Clinicians should overcome potential biases by getting to know each patient as an individual. And when uncertain, clinicians should discuss the decision to withhold information with a trusted member of the patient's inner circle, experienced colleagues, or both.

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