

CASE AND COMMENTARY: PEER-REVIEWED ARTICLE

What Should Clinicians Do When a Patient's Autonomy Undermines Her Being Treated Equitably?

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Abstract

Language and cultural barriers can impede communication between patients and clinicians, exacerbating health inequity. Additional complications can arise when family members, intending to protect their loved ones, ask clinicians to lie or not disclose to patients their diagnoses, prognoses, or intervention options. Clinicians must express respect for patients' and families' cultural, religious, and social norms regarding health care decision making, but they might also be ethically troubled by some decisions' effects on patients' health outcomes. This article suggests strategies for clinicians trying to overcome linguistic and cultural barriers to equitable patient care.

Case

Mrs Z is a 70-year-old Pakistani widow with limited English language proficiency. She came to the United States, where her children live, to have masses in her neck and armpit evaluated. Physical examination and subsequent biopsies revealed an aggressive B-cell lymphoma, a hematologic malignancy uniformly fatal without chemotherapy. Mrs Z is staying with her eldest son (her health care agent) and daughter-in-law and granted them permission to access her health information via the hospital's patient portal.

After accessing Mrs Z's biopsy results, Mrs Z's children told her the masses were not cancer. Her son then asked Mrs Z's caregivers not to reveal to her that she has lymphoma. He explained his and his sibling's intention to protect Mrs Z, strongly believing that she could neither emotionally cope with her diagnosis nor physically tolerate lymphoma treatment. Six years earlier, Mrs Z's younger sister had died from lymphoma, despite aggressive chemotherapy.

Mrs Z's physicians, however, believed it was imperative that oncologists assess her case and develop an individualized treatment plan. Lymphomas, even those diagnosed within the same family, vary in prognoses and treatment options.^{1,2} They informed Mrs Z's children that Mrs Z's experience might not be at all like her sister's. They explained that some lymphomas are indolent and require no or mild treatment, while others are

aggressive and compel immediate attention, without which a patient could die within days.³

Mrs Z's physicians also knew that age is an important factor in predicting treatment response and therefore that discussions with Mrs Z should include risks and benefits of therapy.^{4,5} Lymphoma is mostly treated with cytotoxic agents, and older patients with comorbid conditions generally experience worse outcomes and side effects, such as myelosuppression, cardiac dysfunction, peripheral neuropathy, ileus, steroid-associated complications, and increased risk of treatment-related mortality.^{6,7}

Mrs Z's oncologist and nurse practitioner believed that Mrs Z's decision-making capacity was intact, which means that her son's role as decision maker only comes into play if she does not have the capacity to make a specific medical decision at a specific point in time. They also explained to her son that, with assistance from an interpreter, they could compassionately and thoroughly explain to her the lymphoma diagnosis, along with benefits and risks of treatment options. Mrs Z's son declined both a follow-up appointment with the oncologist and the offer of an interpreter, however. The oncologist and nurse practitioner requested a clinical ethics consultation for guidance and wondered what to do next.

Commentary

Physicians in the United States treat patients from all over the world and have a fiduciary and ethical duty to treat them all equally. This responsibility includes providing them with clear and meaningful information and recommendations and ascertaining and honoring, to the best of their abilities, the health care choices of adult patients who possess decision-making capacity. **Language or cultural barriers** can impede communication between physicians and patients, which can adversely affect the physician-patient relationship, potentially resulting in inequities in health care delivery. Additional complications might arise when family members, with the intent of protecting their loved ones, ask physicians to lie or not disclose to patients their diagnoses, prognoses, or treatment options. While recognizing and respecting the importance of cultural, religious, and social norms in health care decision making, physicians nevertheless may be concerned that **well-intentioned family members** are inappropriately interfering with, or even coopting, the self-determination of adult patients with decision-making capacity. Based on the preceding case, this paper aims to explore such morally challenging situations and to present strategies for addressing linguistic and cultural differences with the goal of helping clinicians provide equitable, ethical, and clinically appropriate patient care.

Practical and Linguistic Considerations

In the United States, more than 25 million people (roughly 9% of the population) are considered as having limited English proficiency (LEP).⁸ From regulatory, clinical, and ethical standpoints, it is imperative that hospitals and other health care settings provide accommodations for patients with LEP, whose rights are guaranteed by multiple regulations, including (but not limited to) the Civil Rights Act of 1964,⁹ the Affordable Care Act,¹⁰ and the National Standards for Culturally and Linguistically Appropriate Services (CLAS).¹¹ Studies have demonstrated that the use of **professional interpreters** improves the quality of care for patients with LEP, resulting in higher patient satisfaction,¹² fewer errors in communication,¹³ reduced disparities in utilization of services,¹⁴ and improved clinical outcomes.^{15,16} Complementary studies have found that relying on nonprofessional interpreters can cause an increase in interpretation errors, such as misinterpretation of information and alteration of key patient details,¹⁷ which

can potentially harm patients.^{16,18} Several studies support the idea that the use of interpreters is not only a quality imperative but also a patient safety imperative.^{16,19,20,21}

The gold standard for communication with patients is matching them with clinicians who are truly fluent in their preferred languages.²² To assist partially fluent or nonfluent clinicians in communicating with patients,^{23,24} most hospitals offer language assistance services, including the next-best practice of in-person professional medical interpreters.²⁵ Other interpretation services include the use of remote professional medical interpreters (via telephone or video links), ad hoc bilingual clinicians, ad hoc bilingual hospital employees²⁶ (other than the treating physician), and bilingual family members. The use of ad hoc staff or volunteer interpreters is justifiable by law only in emergency situations when a credentialed clinician or interpreter cannot be easily accessed. Using untrained individuals or minors as interpreters should be avoided (CLAS standards), and both CLAS standards and the Affordable Care Act state that translators or interpreters must meet specific minimum qualifications, including upholding ethical principles, maintaining confidentiality, and demonstrating proficiency, effective interpretation, and the ability to use specialized terminology as necessary in the health care setting.^{11,27} Federal, state, and many hospitals' policies prohibit bilingual family members' serving as interpreters, except in emergency situations or when explicitly requested by the patient.^{27,28} Under Section 1557 of the Affordable Care Act, anyone functioning as an interpreter must undergo a language skills assessment and interpreter training.¹⁰ Table 1 highlights the advantages and disadvantages of various types of available language assistance.

Table 1. Sources of Language Assistance for LEP Patients^a

Type and Description	Advantages	Disadvantages
Professional In-person Medical Interpreter (Highest standard on-site medical interpretation service)	<ul style="list-style-type: none"> Optimal medical and interpreter training National medical interpreter certification Adherence to professional oath and code of ethics²⁹ 	<ul style="list-style-type: none"> Availability depends on location and time of day Limited language availability
Professional Telephonic Medical Interpreter (Usually available through a landline phone, mobile phone, or dedicated device)	<ul style="list-style-type: none"> Similar training, certification, and requirements as in-person interpreters Available 24/7 	<ul style="list-style-type: none"> Impersonal; interpreter cannot read body language or visual cues Potential technology problems and lags Difficult for patients with hearing or cognitive impairments or delirium
Professional Video Medical Interpreter (Available through a video-capable device)	<ul style="list-style-type: none"> Similar training, certification, and requirements as in-person interpreters More personal and better-equipped to read visual cues than telephonic services 	<ul style="list-style-type: none"> Limited availability, languages, and hours of operation Potential technology problems and lags
Bilingual Clinician (Clinician fluent in the language of the patient)	<ul style="list-style-type: none"> Time-saving High level of comfort and familiarity Evidence of improved care and outcomes³⁰ 	<ul style="list-style-type: none"> Clinician's language skills unproven Potential biases and role confusion

Ad hoc or Dual-Role Interpreter (Nonclinician hospital staff member available to assist when other interpreters are unavailable)	<ul style="list-style-type: none"> • Potentially time-saving • Potentially more personal if preexisting relationship with patient exists 	<ul style="list-style-type: none"> • Unfamiliarity with medical terminology may lead to errors • Proficiency in target language unproven • Concerns about confidentiality, bias, omissions, and inappropriate editing
Bilingual Family Member or Friend (Affiliate who self-reports bilingual skills)	<ul style="list-style-type: none"> • Time-saving, convenient • High level of comfort and familiarity 	<ul style="list-style-type: none"> • Same concerns as for ad hoc or dual-role interpreters • Potential role confusion • May impede frank discussions between patient and physician

^a Adapted from American Medical Association,³¹ Hsieh E,³² National Council on Interpreting in Health Care.³³

Relying on family members to serve as interpreters can present clinical and ethical pitfalls. As exemplified by this case, family members often assume the role of interpreter as a means of convenience and comfort during what can be a stressful clinical encounter. However, family members who are not familiar with medical terminology or whose English (or target language) skills are limited can inadvertently cause harm to patients through interpretation errors, misunderstandings, or omissions.³⁴ Other subtler, yet still potentially harmful, risks include inappropriate editing or polishing of a patient’s information or an injection (intentionally or unintentionally) of bias into the interpretation. Moreover, some patients might be reluctant to discuss embarrassing or sensitive information in front of their relatives and omit vital clinical information, which could impair an open patient-clinician relationship.^{18,35,36}

Patient autonomy might also be compromised when family members serve as interpreters. The case of Mrs Z serves as an extreme example of a patient whose voice has been effectively silenced. Professional medical interpreters are better equipped to respect patient autonomy. They have no personal relationships with patients, which allows them to focus solely on their professional clinical responsibilities, and are well trained in clinical terminology, hospital and governing rules regarding patient privacy (such as the Health Insurance Portability and Accountability Act), state and federal mandates, and their own code of ethics.²⁹ In contrast, family members must play several difficult and emotionally charged roles with patients: they are caregivers, comforters, negotiators, conciliators, and logicians. Adding interpreter to the list of responsibilities increases their burdens and might detract from their ability to provide their loved ones with necessary emotional support.³⁷

Cultural and Ethical Considerations

The case of Mrs Z also illuminates the ethical challenges that can arise in the context of cultural differences between physicians and patients and the importance of recognizing and upholding the ethical principles of autonomy and relational autonomy, truth telling, and the right not to know.

Autonomy. The principle of autonomy obligates physicians to provide patients with clear and meaningful information about their condition and to recommend pertinent diagnostic and therapeutic options. Physicians respect patients and abide by the principle of autonomy by appraising the abilities of adult patients to (a) deliberate upon or intellectualize the information they receive, (b) discriminate between the recommended treatment options, and (c) act intentionally, free from the controlling influence of others and in accordance with their own beliefs and values.^{38,39,40}

Relational autonomy. Physicians must also acknowledge that individuals' identity, needs, interests, and autonomous preferences are shaped by their relationships with others.³⁹ Individuals exist in socially embedded networks and relationships through which they develop their individual sense of self, their preferences, and their life plans, along with their social sense of responsibility, stewardship, and interdependence. This framework is often referred to as *relational autonomy*.⁴¹ In essence, relational autonomy is an expression of individual autonomy that can be exercised through group decision making or even through ceding decision making to others. In Mrs Z's case, social, familial, religious, and cultural influences might shape her autonomous decision to relinquish decision making about disclosure of medical information and treatments to her son. However, physicians should not infer the decision-making preferences of patients with LEP. They should approach patients with LEP with questions such as: "How would you like us to convey information—to you, your family, or both?" Or, "How have you made medical decisions in the past? How would you like to make them now?"

Truth telling and the right not to know. Truth telling by health care professionals is a foundation of the bioethical principles of autonomy, beneficence, and justice. Patient autonomy is predicated on patients knowing and appreciating their medical status and treatment options; without this cognizance, they are at risk of harm. The right to one's medical information can be interpreted as a basic human right, as exemplified by the 1997 European Convention on Human Rights and Biomedicine: "Everyone is entitled to know any information collected about his or her health."⁴²

As with all bioethical principles, however, truth telling must be placed in context. Respecting patient autonomy does not imply a "one-size-fits-all" approach to truth telling or require "truth dumping"—the disclosure of all aspects of a disease or treatments without regard for a patient's needs or desire for information.⁴³ Disclosure must take into consideration the patient's stated preferences for receiving information, making decisions, and family involvement.^{43,44,45,46} The right *not* to know one's medical diagnosis, prognosis, or treatment options is also endorsed by the European Convention on Human Rights and Biomedicine: "the wishes of individuals not to be so informed [about their health] shall be observed."⁴² Although some clinicians might interpret this preference as Panglossian, counterproductive, or even harmful, they must respect that sometimes the autonomous choice of an adult patient with decision-making capacity is to not know or to delegate truth telling to a surrogate. Faced with the prospect of an incurable disease, some individuals might consider the burden of knowledge to be unbearable; disclosure can lead to severe depression and negatively affect family and social life.⁴⁷

Several published accounts address **cultural norms and the role of family** in receiving, conveying, and deciding on disclosure of medical information and interventions.^{44,48,49} A key theme is that disclosure to patients alone, without family present, is a characteristically Western or allopathic phenomenon and that in many countries—both economically developed and less economically developed—the family is the primary recipient of a diagnosis; the question is often whether the patient should be told in addition to the family.^{30,50,51,52} Although clinicians should recognize the religious, cultural, and social contexts of their patients and families, they should not assume that these contexts unwaveringly dictate their patients' health care choices. Patients' preferences are individualistic, and physicians must treat them as such. Several studies have found that while many patients recognize the inherent legitimacy and importance of nondisclosure in their culture, they personally wish to be involved in their own health care decisions.^{30,44,48,53} One must not automatically infer that Mrs Z's age, culture, and religion dictate her health care preferences. By the same token, physicians and other

health care professionals should not try to impose their own culturally based disclosure preferences on the patient.

Recommendations

The following are suggestions for engaging patients and family members in productive, open dialogues, which may serve to improve patient care and reduce disparities that can occur in the presence of linguistic or cultural differences (see Table 2).⁵⁴

Table 2. Responses to a Family’s Request to Hide the Truth from a Patient^a

Strategy	Example
Do Not Overreact	<ul style="list-style-type: none"> Resist the impulse to say: <i>This is not how we do things here—we must tell your mother her diagnosis.</i>
Listen	<ul style="list-style-type: none"> Try to learn whether the family’s request is a manifestation of its own fears or distress. Try to learn whether the request is prompted by the family feeling responsible for shouldering the burdens of worry, despair, or responsibility for difficult decisions.
Acknowledge	<ul style="list-style-type: none"> <i>I see how much you and your family love your mother.</i> <i>I appreciate your wanting to shield your mother from harm.</i>
Empathize	<ul style="list-style-type: none"> <i>I share the same goal of wanting to keep your mother from harm.</i> <i>I want to do everything possible for your mother’s well-being.</i>
Relate	<ul style="list-style-type: none"> <i>Truthfulness is vital to me as both a physician and a human.</i>
Offer Suggestions	<ul style="list-style-type: none"> Promote an atmosphere of open dialogue, which will enable the medical team to better serve the patient. When eliciting the patient’s disclosure preferences, remember that the diagnosis does not need to be revealed. Consider using professional medical interpreters, which are beneficial for both the patient and the family. Offer additional support services, such as chaplaincy, social work, and patient representatives, which are available to help both the patient and the family cope during this stressful time. Seek to understand the level of involvement the patient would like to have in making decisions or whether the patient wants to defer to the family.

^aAdapted from Hallenbeck J, Arnold R.⁴⁴

Engage patients in discussion of their preferences as early as possible. Physicians should engage patients in open, well-documented dialogues about their preferences regarding disclosure of diagnoses and other medical information as early as possible in the patient-clinician relationship—even before patients’ hospital admission—preferably with a qualified interpreter present.⁵⁵ Doing so will promote equity; enable culturally appropriate, patient-centered care; and potentially prevent future requests for nondisclosure by family members. Unfortunately, time and logistical constraints might impede a physician from securing a medical interpreter for these preemptive discussions. Ideally, knowing a patient’s LEP status in advance might help physicians and institutions better prepare for consultations.

Proactively suggest engaging a medical interpreter. At the beginning of the consultation, physicians should inform patients and families about the availability of professional medical interpreters as essential resources in the delivery of high-quality, equitable, and patient- and family-centered care. They should stress that relying on professional

interpreters does not preclude family members from participating in encounters, nor is it a sign of the family's weakness or incompetency. Rather, it is a means of ensuring the best possible care. Physicians might nevertheless encounter resistance from families, who might consider interpreter services—particularly those that must be accessed remotely via telephone, video, or other platforms—to be too impersonal, unsatisfying, or complicated.

Engage reluctant or contentious family members in a calm, productive manner, utilizing ethics consultations or other supportive services. Preemptive discussions are not always feasible, and often, as with Mrs Z, circumstances make it difficult to ascertain the patient's preferences. In these circumstances, physicians should work to engage the family in a calm, productive dialogue and engage ethics consultants or other supportive services, such as social work or chaplaincy.

Do not overreact to family requests for lying or nondisclosure. It is critical to resist the impulse to respond to requests for nondisclosure with: "Absolutely not. This is not how we do things here." The family might interpret this as a criticism, resulting in an escalation of the conflict⁴⁴ or a total cessation of communication—both of which could ultimately cause harm to the patient.

Listen. Try to ascertain the family's concerns and reasons behind its request for nondisclosure. The request might be a reaction to the family's fears and distress at its loved one's diagnosis or a manifestation of a sense of duty to relieve the patient of the burden of worry, loss of hope, and responsibility for difficult decisions.⁴⁴

Acknowledge, empathize, and relate. Compassionate and empathetic responses, such as "I appreciate your wanting to protect your mother from harm. I share that goal,"⁴⁴ will go a long way in conveying that you have the patient's best interest at heart. Furthermore, explaining how truthfulness is vital to you as a human being might allow the family to relate to you as a person, not just as a physician.

Offer other suggestions. Prevent framing the response to the request for nondisclosure as a zero-sum argument.⁴⁴ Instead, explain how the medical team will be better able to serve the patient in an atmosphere of open dialogue. Discuss strategies that allow patients to voice their preferences regarding disclosure and decision making and explain that eliciting their preferences can be done respectfully, without revealing the diagnosis. Explain how medical interpreters improve health equity and benefit both the patient and the family by removing burdensome interpreter responsibilities and allowing the family to focus on emotionally supporting the patient. Finally, discuss additional support services, such as chaplaincy, patient representatives, and social work, which are available to help the patient and family during this stressful time. Despite physicians' best efforts to utilize these strategies in a compassionate and respectful manner, physicians can still be unsuccessful in forming therapeutic alliances with families. Family members might remain adamant that the patient not be told her diagnosis, maintaining that they, as her loved ones and penultimate support system, know what is in her best interest. Physicians might continue to grapple with how, under such circumstances, to deliver just and equitable care for the patient in a clinically and ethically appropriate manner. Hospital ethics committees and additional support services might be helpful in this endeavor.

Conclusion

Linguistic or cultural differences should never prevent patients from receiving health care that is clinically and ethically appropriate as well as equitable. Physicians have a

moral and fiduciary responsibility to attempt to address these potential impediments to ascertain how patients prefer to receive information and to make decisions about their care. Toward this end, physicians should employ available resources, such as professional medical interpreters and other institutional services, while maintaining an awareness of, and respect for, patients' and families' unique cultural or social dynamics.

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Editors Note

The case to which this commentary is a response was developed by the editorial staff.

Citation

AMA J Ethics. 2021;23(2):E97-108.

DOI

10.1001/amajethics.2021.97.

Conflict of Interest Disclosure

The author(s) had no relevant conflicts of interest to disclose.

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