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Truth Telling in the Setting of Cultural Differences and Incurable Pediatric Illness

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Abstract

IMPORTANCE—Navigating requests from parents or family caregivers not to disclose poor prognosis to seriously ill children can be challenging, especially when the requests seem culturally mediated. Pediatric clinicians must balance obligations to respect individual patient autonomy, professional truth telling, and tolerance of multicultural values.

OBSERVATIONS—To provide suggestions for respectful and ethically appropriate responses to nondisclosure requests, we used a hypothetical case example of a Middle Eastern adolescent patient with incurable cancer and conducted an ethical analysis incorporating (1) evidence from both Western and Middle Eastern medical literature and (2) theories of cultural relativism and justice. While Western medical literature tends to prioritize patient autonomy and corresponding truth telling, the weight of evidence from the Middle East suggests high variability between and within individual countries, patient-physician relationships, and families regarding truth-telling practices and preferences. A common reason for nondisclosure in both populations is protecting

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the child from distressing information. Cultural relativism fosters tolerance of diverse beliefs and behaviors by forbidding judgment on foreign societal codes of conduct. It does not justify assumptions that all individuals within a single culture share the same values, nor does it demand that clinicians sacrifice their own codes of conduct out of cultural respect. We suggest some phrases that may help clinicians explore motivations behind nondisclosure requests and gently confront conflict in order to serve the patient's best interest.

CONCLUSIONS AND RELEVANCE—It is sometimes ethically permissible to defer to family values regarding nondisclosure, but such deferral is not unique to cultural differences. Early setting of expectations and boundaries, as well as ongoing exploration of family and health care professional concerns, may mitigate conflict.

In this hypothetical case, Sara was 15 years old when she was diagnosed as having advanced liver cancer. Despite cure-directed chemotherapy in her home Middle Eastern country, her disease progressed. Her mother and uncle brought her to the United States for additional treatment.

During initial conversations between the new US-based health care team and Sara's family, Sara's uncle described his role as the family's medical decision maker. Here quested that Sara not be told about her cancer's progressive or incurable nature. He explained that additional disclosure would only cause her suffering.

Over time, medical staff raised concerns about 2 issues. First, respecting Sara's evolving autonomy: should she be told about her worsening disease to allow her opportunities to participate in decision making and legacy building? Second, respecting clinicians' professional integrity around truth telling: if she were to ask medical staff directly what was happening to her, should they not be truthful? When these concerns were presented to Sara's uncle, he remained consistent in his request for secrecy, even as Sara's family transitioned their goals from cure-directed to comfort care.

Cases like Sara's arise owing to clashes between differing cultural values; health care professionals (HCPs) strive to balance obligations of respect for individual patient autonomy, professional truth telling, and tolerance of multicultural or community traditions. In this essay, we first examine alternative perspectives regarding truth telling, reviewing the empirical literature from both Western and non-Western perspectives. We then discuss the concept and limitations of cultural relativism in medical settings. We then turn to justice theory to support our view that deference to family values (including nondisclosure) is ethically permissible in some cases, but not owing to special deference to cultural differences. Finally, we suggest several resources and phrases that help clinicians navigate these circumstances and meet universally shared goals of serving the patient's best interest.

Alternative Perspectives

US Medical Perspectives

Truth-telling practices within American medicine have evolved. In the 1960s, most physicians believed that disclosing a cancer diagnosis could be overly distressing and potentially harmful to patients, with 90% preferring nondisclosure.[1] By the late 1970s,

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however, a complete reversal of opinion had occurred, with nearly 100% of surveyed physicians reporting full disclosures of cancer diagnoses.[1] In 1980, the concept of honesty officially became part of the American Medical Association's professional code.[2] Today, 98% of American medical oncologists (serving adults) believe disclosure is an ethical imperative.[3]

The primary value underlying medical practice, the patient's best interest, did not shift between 1960 and 1980. What changed was a growing recognition that nondisclosure did not always serve this purpose.[4] While physicians in the early 1960s believed that disclosure could do irreparable harm to patients, this belief was undermined as evidence suggested most patients (1) were already aware of their serious diagnosis; (2) imagined the worst in the absence of specific details; and (3) were denied both opportunities to make plans for the future as well as an open and honest environment to explore their fears and hopes.[4] Over time, physicians realized that nondisclosure rarely benefitted patients and, in some cases, caused harm. Hence, rather than a dramatic shift in the cultural values or ethical principles, physicians learned how to better serve the good of the patient.

We also have come to understand physician motivations in these often difficult conversations. Nearly half of pediatric oncologists associate a patient's impending death with personal failure.[5] In addition, many US physician incentives are based on patient satisfaction; thus, physicians may have motivations to delay, if not entirely avoid, disclosure of upsetting news.[6] Regardless of its validity, adult patients report more confidence in physicians after hearing optimistic, compared with pessimistic, information.[7,8] Not surprisingly, many physicians tend to be vague, overly optimistic, and focus on treatment options (rather than their outcomes).[9–11] The end result is that many patients with advanced cancer remain unaware of their prognosis.[12]

Deliberately withholding the truth has negative consequences, even if done with the intent of kindness; most US adults consider the idea of nondisclosure "unacceptable."[13] Nondisclosure may also be counter productive; patients and families cannot make fully informed decisions without fully understanding prognosis and the potential benefits and burdens of treatment. Patients may make ungrounded requests for treatments[14] and, in turn, suffer from toxic therapies or regret their decisions.[15–18] Indeed, many care-givers of children with cancer continue to look for and suggest treatment options until the time of the child's death,[19] and nearly half of medical oncologists provide treatments they know are unlikely to work.[20] One-third of parents believe they did not receive enough prognostic information to make an informed decision about their child's cancer care[16]; those who receive detailed prognostic information have significantly lower odds of later decisional regret.[17]

No matter how good or bad the news, when physicians deliver complete and honest prognostic information about the child's cancer, parents trust them more.[9,21] Physician truth telling has also been associated with less long-term parent distress, especially when it enabled care decisions that were aligned with patient and family values.[16,22,23]

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Several studies from Western cultures suggest that adolescents like Sara not only want to hear complete prognostic information early or in tandem with their parents, but also that they are capable of thoughtful and mature decision making and want to be involved in decisions related to their care.[24–29] Adolescents have further stated that being aware of options and having opportunities to participate in advance care planning are concrete priorities.[25] This is not to say that all adolescent patients want all of the available information. For example, although most agree they have "a right" to know, a subset say they would prefer not to know such information about themselves.[28] A recent study suggested that many teens prefer to have information filtered to them from family members or loved ones.[26] This finding emphasizes the importance of determining an individual adolescent's preferences for specific types of health-related information, including prognosis.

Finally, difficult news is almost always distressing to patients and families; but it neither lessens hope nor leads to lasting psycho-pathology.[30,31] It also may take time for complete understanding to take root. On average, physicians understand a child's poor prognosis 100 days before parents do.[32] The sooner and more often the truth is spoken, the sooner and more consistently a family can begin to process the information and make corresponding decisions. Current recommendations include delivering information in small, manageable pieces, as well as engaging in frequent discussions to support the family's evolving prognostic awareness.[33] In almost all cases, these recommendations also encourage full disclosure, even when patients and families ask not to hear it.[4,34]

Multicultural Perspectives

Although comparatively less is known about global, community-based preferences for disclosure, several studies suggest immediate deference to individual patient autonomy is specific to Western cultures.[35,36] Systematic reviews suggest collusion (defined as a cultural practice in which family members request withholding information from the patient) is common in regions where families, rather than individual patients, are considered the central unit of medical decision making.[35] Empirical research describing culturally based family preferences for collusion regarding a diagnosis of cancer has come from all over the world, including Asia,[37–41] Africa,[42] Europe,[43–45] and the Middle East.[46–48]

Requests for collusion by non-native families receiving medical care in Western societies are also well-described.[47,49–54] These and other cultural differences are commonly cited as barriers to appropriate end-of-life care.[55] Additional literature suggests how Western HCPs should respond to noncollusion requests.[4,35,56,57] Broadly, guidelines recognize that (1) individual autonomy may be less critical in some cultures than others and (2) cultural values are part of patient-centered, compassionate care. At a minimum, being open to diverse perspectives allows for rapport building and collaborative relationships with families. At worst, disregarding cultural values may damage working alliances and negatively impact the quality of care.

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Middle Eastern Cultural Norms

Hence, caring for Sara warrants some focus on her cultural norms. Although some authors suggest Middle Eastern cultural norms are consistent among patients and families and commonly defined by religion and community,[56] a comprehensive review of literature from Egypt, Iran, Israel and Palestine, Jordan, Lebanon, Kuwait, Pakistan, Saudi Arabia, Turkey, and the United Arab Emirates suggests that Middle Eastern attitudes about truth telling are variable.[48]

First, patient perspectives may differ by country or patient age. For example, only 52% of Pakistani citizens would want complete details of their diagnosis.[58] In contrast, 88% of Turkish patients want full prognostic disclosure,[59] 87% state they have rights to such information, and 92% believe physicians are obligated to deliver it.[60] Although descriptions of the perspectives of adolescents like Sara are lacking, a study of young adult Saudi Arabian medical students, who were closer to Sara's age than typical older study populations, suggested 93% would want to know about a diagnosis of cancer.[61]

Second, physician practices vary within and across Middle Eastern countries.[62–70] Israeli studies have found differences in disclosure practices based on specialty and experience.[71] For example, 61% of subspecialists "always disclose" to their patients, whereas 25% of family practitioners do the same. In Kuwait, 67% of physicians endorse disclosure practices compared with nearly the opposite in Pakistan.[67,72] In Pakistan, reasons for nondisclosure center on beliefs that disclosure would cause undue psychological distress.[72]

Studies describing family beliefs corroborate this concern. In many Middle Eastern communities, caregivers endorse an obligation to protect patients from bad news.[56] Because of its stigma, cancer disclosures are considered cruel.[73] Although almost all Turkish patients believe physicians are obligated to disclose prognostic information,[60] more than half of Turkish caregivers believe patients should not be told of their diagnosis because it contributes to psychological distress.[74] This may be because several studies suggest associations between prognostic disclosure and patient distress, psychopathology, or poorer quality of life.[75–79] Interestingly, the authors of these studies attribute the distress not to the content of the information, but with the way in which it was delivered. For example, distress has been associated with incomplete information[75,76] and misrepresentations of the illness[80] rather than disclosure itself.

Finally, the trend toward truthful disclosure observed over time in Western settings has also been evident in parts of the Middle East. In Lebanon, a code of medical ethics was established in 1995, followed by a 2004 law requiring informed consent.[48] In 1998, 47% of Lebanese physicians reported disclosure practices.[81] By 2007, 99% believed that disclosure to patients and families should be standard,[70] and Lebanese patients reported that, although the experience was stressful, they still had a right to know the information.[82]

This evolution of preferences toward truth telling has also been described in Saudi Arabia. For example, in 1997, 75% of Saudi Arabian physicians preferred speaking with family members over patients, and only 47% disclosed serious prognosis directly to patients.[83] In 2008, 67% of physicians deferred to individual patient's requests to inform family members

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(or not). Notably, most patients still preferred a family-centered model of care.[84] In 2009, a study assessing preferences of 114 adults with cancer in Saudi Arabia demonstrated that all wanted to know their prognosis and 113 (99%) wanted "full" (rather than "partial") information.[85] These shifting preferences have been largely attributed to public education and evolving "cultural openness."[73]

Cultural Relativism

Cultural relativism suggests that different societies have different codes of conduct and moral standards. Therefore, no universal code or standard (Western or otherwise) can be used validly to judge others.[86] The ensuing principles of multiculturalism include promotion of diversity, minimization of prejudice, and respect for divergent cultural practices.[87]

By denying the existence of a "higher" or universal set of ethical standards, cultural relativism poses a challenge for those in Western medicine who would argue that patients and their families should be expected to behave on the basis of Western values and norms. From the perspective of cultural relativism, assuming that Western truth-telling practices should override other cultural norms of collusion is arrogant and insensitive. As applied to Sara's case, this suggests that Western HCPs have no grounds for imposing their beliefs about diagnostic disclosure on Sara's family. Worse, imposing disclosure on Sara and/or her family could lead to harm. As previously described, most of the world embraces value systems that prioritize the welfare of family and community above that of individual persons. Thus, the values of Western medicine should be open to challenge.[87] Some might argue that Western bioethical frameworks represent the global minority and therefore should be subject to reasonable criticism.[88]

Limits of Cultural Relativism

While cultural relativism poses a reasonable challenge to those who would impose their own cultural norms on individuals outside of their culture, the cultural relativism approach also contains some serious shortcomings. Assuming that all cultural norms are equally correct, cultural relativism precludes the recognition of universal norms and rights. Activities across the spectrum of human rights protections, from abolishing slavery or preventing genocide to advancing the standing and liberty of people who have confronted discrimination and bigotry, require both affirming certain values while rejecting others. Cultural relativism does not adequately answer the question: when are we obligated to be intolerant of cultural differences? The principle of justice suggests that persons from different cultural, religious, and ethnic groups must be treated fairly, but—importantly—does not require that specific cultural practices always be tolerated equally.[87]

In Sara's case, endorsing cultural relativism could lead to 3 erroneous assumptions. First, if we accept Sara's uncle's views as culturally representative (and we subsequently strive to meet his requests), then we must also conclude his views are the same as Sara's. However, the literature suggests high intracommunity and intra-family variability regarding truth-telling preferences. Furthermore, studies of immigrant cultures suggest that those born and raised in the United States tend to align more with Western preferences of truth-telling

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practices, whereas those who emigrated as adults tend to adhere to their prior traditions of collusion.[89] Having been in the United States for some time may have already influenced Sara's views. Hence, cultural relativism risks over generalization, if not outright inappropriate cultural stereotyping.

Second, if cultural relativism suggests HCPs suspend judgment to meet culturally divergent requests, it also assumes HCPs may ignore their own values and professional integrity. If HCPs ought not impose their beliefs on Sara's family, why would Sara's family be allowed to impose its own values in reverse? If asked explicitly to lie to Sara about her prognosis, would a US HCP be obligated to do so? At face value, cultural relativism precludes cultural compromise.

Third, we cannot assume that specific or local culture alone defines motives; certain notions or values rooted in transcultural beliefs or human psychology may shape behavior. Across cultures, childhood death is difficult because it ignores the natural order of the human life cycle and threatens parental roles of protecting offspring.[90] Parental requests for nondisclosure are well-described in Western settings; they are not culturally specific.[4] Sara's uncle's request for collusion may be grounded in a deep-seated drive to protect her from harm. If so, his actions do not necessarily represent a unique cultural view, but instead represent one possible response to a transcultural commonality.

Navigating Differences

Curiosity

Perhaps an alternative way to navigate cultural differences is to identify these shared, more universal values across human societies.[91] In cases like Sara's, rather than fixate on the rightness or wrongness of immediate disclosure vs collusion, HCPs might explore her family's needs, values, and reasons behind the request (Table 1). This demands cultural curiosity ("When you consider telling Sara about her cancer, what worries you?"). Curiosity also requires time and thoughtful consideration of whether disclosure promotes or hinders Sara's welfare, as well as others who may be affected by it (eg, her uncle, mother, and her home community in the Middle East). As practitioners of family-centered care, pediatricians are uniquely situated to engage in this practice.[92]

Such an approach may facilitate an alliance with the family (both sharing of expectations and cultural norms), while also enabling Sara's voice and values to take shape. While Sara should be given opportunities to express her own needs and values, she must also be allowed to defer information delivery to her surrogates. Such a decision is autonomous and should be respected.[87]

Confrontation

Although Western-based medical staff should endeavor to be culturally respectful and explore patient/family/community values and practices, they are under no obligation to provide care they feel is unethical or harmful,[93] nor are they disallowed from respectfully questioning patient and family decisions.[94] ("Would you be okay if I told you what worries me about not telling Sara about her cancer?")

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To avoid conflict, HCPs should respect fully set expectations early in a relationship (Table 2). For example, families traveling to the United States for care could receive descriptions of medical systems and values. During early conversations, this information should include discussion of boundaries for both families and HCPs. In Sara's case, her HCPs might have explained that Western practice often involves asking Sara directly how she prefers to hear information. A similar statement might be if she asked directly, her HCPs would not lie. Ensuing conversations could include explorations of how to handle these situations if they arise. Setting these expectations in advance of specific decisions may lessen, if not prevent, conflicts that could arise later.

Collaboration

After much discussion with Sara's family, health care staff asked her privately how she preferred to receive information. She stated she wanted to hear news directly from her family members and agreed that her uncle was her preferred designee.

Truth telling in the setting of incurable illness is always difficult for health care staff, patients, and families. It may be additionally difficult when cultural differences in preferences and practices arise, especially surrounding the care of a minor. While respecting cultural differences and treating individual communities equally is a necessary concept of justice, there may be times where justice requires that certain cultural practices not be tolerated. Instead, HCPs and families must commit the time and effort for deliberative communication that (1) explores individual and shared values; (2) sets expectations and boundaries; and (3) allows for evolving moral opinions and needs.

Conclusions

Patient- and family-centered care requires reciprocal curiosity and a willingness to share, listen, and compromise. These processes are not specific to cultural differences and, in the end, may facilitate more successful collaborations between patients, families, and HCPs, in turn improving the care we deliver.

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Table 1

Phrases That Help Facilitate Exploration of Cultural Perspectives, Values, and Information Needs

Domain	Sample Phrases to Introduce the Conversation
Cultural perspectives and values	“Can you please tell me about your culture/community/faith?”
	“Can you tell me a little about yourself and what is important to you in your life?”
	“Can you tell me about your experiences in your home community in situations like this?”
	“When you think about what is ahead, what worries you most?”
Information delivery	“Different people/families like to hear information in different ways. Can you please share how you like to receive information?”
	“Are there particular people who you would like us to include when we share medical information?”
	“Are there particular people who you would like us to not include when we share medical information?”
Decision making	“Can you please share with me how you and your family make decisions?”
	“When you have made medical decisions in the past, what were the circumstances that worked best for you?”
In cases of conflicting values (eg, requests for collusion)	“When you think about telling [patient] about her [diagnosis], what worries you most?”
	“Would you mind telling me more about why you don’t want [patient] to know about her [diagnosis]?”
	“When you think about what is ahead, what are you hoping for?”
	“Would it be okay if I told you what worries me about not telling her about her cancer?”

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Table 2

Suggestions to Alleviate Distress and Minimize Conflict

Issue to Consider	When to Consider the Issue	Conversations That May Minimize Conflict	Why The Conversation May Minimize Conflict
A family coming from another country may not be familiar with Western practices	During discussion with referring team (prior to a transfer of care)	Simple but clear descriptions of how your system works (eg, "Our hospital is a teaching hospital and carefully supervised students will be part of your care team.").	Some aspects of Western care may feel frightening and unfamiliar to new families; providing an opportunity to explain the systems and safeguards may avoid later confusion and discomfort.
		Disclosure of norms (eg, "When we take care of adolescents, we try hard to understand their needs, as well as those of their whole family. This often means that we talk directly to the adolescent himself or herself.").	Advanced discussion and explanation of Western practices and values opens the door to mutual sharing and explorations of family needs. This process may also avoid later misunderstandings, including heightened patient and family anxiety that is often associated with nondisclosure.
A family prefers that prognostic information be withheld from an adolescent patient	During early conversations with the family	Exploration of cultural values and prior experiences, rationale for family's request (eg, "I can see how much you want to protect your daughter. What do you think might happen if we talked to her directly?").	Exploring shared values of the child's best interests may help align parents and HCPs, plus open doors to conversations about possible positive consequences of truth telling including alleviating the child's fears and understanding the child's wishes.
		Exploration of what to do if the adolescent asks directly about her prognosis or disease status (eg, "It is important that [patient] know she can trust me, so I would like to answer honestly if she asks me.").	Advanced discussion about "what ifs" can prevent staff anxiety about courses of action and help prepare for contingencies.
	When the child's disease worsens	Sharing prior experiences, either from the medical team's perspective or by enlisting a trusted member of the community who is familiar with Western hospitals and practices (eg, "Would it be helpful to talk about how other families have navigated this difficult situation?").	Normalizing the difficulty and providing perspectives of other members of the cultural community may alleviate feelings of isolation and provide some acceptable options to families.
		Sharing common pitfalls resulting from nondisclosure, including inconsistent messaging from multiple HCPs, child hearing inadvertent news from staff or other patients, child taking cue from parents not to talk about a taboo topic despite internal needs to do so, child drawing incorrect conclusions from social media or internet (eg, "Would it be okay if I share with you some of the possible problems that sometimes arise in these situations?").	Anticipating issues may facilitate conversation and, ultimately, disclosure on parents' own terms and in a safe/controlled setting.
		Ongoing involvement of the initial and trusted care team via periodic telecommunication or in-person visits.	This may serve dual roles: (1) to assure that all HCPs are on the same page and (2) to reinforce the current approach to the patient/family.

Abbreviation: HCPs, health care professionals.