Withholding Information to Protect a Loved One

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Parents respond to the death of a child in very different ways. Some parents may be violent or angry, some sad and tearful, some quiet and withdrawn, and some frankly delusional. We present a case in which a father’s reaction to his daughter’s death is a desire to protect his wife from the stressful information. The wife is in the second trimester of a high-risk pregnancy and so is particularly fragile. We asked pediatricians and bioethicists to discuss the ways in which they might respond to the father’s understandable but troubling request.

The death of a young child is one of the most stressful events that can happen to parents. The stress of such a loss is compounded if the parents are in a foreign country, far from home, and without a network of family and friends to provide social support. The stress may be more difficult to deal with if the parents have acute health problems of their own. In this month’s “Ethics Rounds,” we present a case in which a father whose daughter died requested that the doctors delay telling his wife. His reason: She is pregnant, in the second trimester, and on bed rest because of preterm labor. He does not want to add to her stress. We asked both pediatricians and bioethicists to respond to this request.

THE CASE

A 7-year-old Bangladeshi child has acute myelogenous leukemia. After initial treatment in Bangladesh, she is brought to the United States, where she undergoes a haploidentical stem cell transplant. Neither she nor her parents speak English. They are staying with relatives. Three months after transplant, the 7-year-old is still in the hospital with delayed engraftment and profound immunosuppression.

Her mother, who is 28 weeks pregnant, has been on strict home bed rest with preterm labor for the past month. She has been unable to come to the hospital. The father is at his daughter’s bedside most days, although he also has to go home periodically to care for his wife. They have no other children.

The 7-year-old develops fever, hypotension, metabolic acidosis, and mental status changes. She is given broad-spectrum antibiotics, aggressive fluid resuscitation, and vasoactive infusions for presumed septic shock. She continues to worsen. During intubation, she becomes hypotensive, bradycardic, and then pulseless. After an hour of resuscitative efforts without a return of circulation, she is declared dead.

The oncology and ICU teams meet with her father. Through an interpreter, he expresses his gratitude for the attempts to save his daughter. The oncology social worker offers to help him talk to his wife. He requests that she not be told at this point. He feels that the stress of their daughter’s illness had caused his wife’s preterm labor. He worries that the news of her daughter’s death will be overwhelming and that she will lose...
the baby. The father emphatically pleads with the teams to hold off informing his wife until she is at 30 weeks’ gestation. He will continue to come to the hospital as if he were spending time with his daughter and will give his wife the news in a few weeks.

Should the medical team allow this delay in informing the mother of her daughter’s death?

Drs Todd J. Kilbaugh and Wynne Morrison respond:

Almost any emotional response from a parent whose child has just died is to be expected. Grief is expressed in many different ways. Some parents may be angry, some sobbing, some quiet, and some frankly delusional. Thinking about the ethically appropriate course of action in this case has to begin with an acknowledgment of the emotional context: This father is suffering, and he is trying to protect his wife and his unborn child.

Although his request is emotionally understandable, it raises serious ethical questions. From a purely ethical and legal standpoint, his wife has as much right to know all the details of her child’s medical care as he does, including information about her child’s death. It just happened to be the case that the father was the parent at the bedside at the time of death and was therefore informed first. She herself could choose to relinquish her right to be informed, however. If she had told the team previously that the details of the medical care were overwhelming for her and that she preferred all information to go through her husband, it would be perfectly reasonable for the medical staff to proceed in that fashion for day-to-day care. Unfortunately, even if such a conversation had happened, one could not assume that a request to remain uninformed should be extended to the specific circumstance of the child’s death.

Cultural issues are probably important in this case, and considering them may help inform the team’s thoughts. Discussing death is avoided in some cultures, and in others pregnant women are discouraged from attending funerals. Overgeneralizations should be avoided; although knowledge of how other Bangladeshi families might approach this situation can be useful, this request might seem unusual even to another family from the same cultural background. Hospital interpreters can sometimes be a good source of information about typical cultural rituals surrounding death, although again the team should not make assumptions about an individual family’s perspective. It may also be a common cultural assumption that the husband can speak for the wife and that he can control what information she receives. As in all cross-cultural interactions, it is important for the team to be aware that perspectives may differ and to respect differences. However, arguing that an action is culturally consistent does not make it ethically justifiable.

Although the feasibility of a particular course of action does not equate with its moral acceptability, the father’s opinion in this case might be swayed if the team outlines their concerns about the logistical difficulties of nondisclosure as a reinforcement of their ethical concerns. It would probably be impossible to keep the information from the mother. The staff cannot be asked to lie or to pretend that they are caring for a patient they are not; even if asked to do so, maintaining such a charade for weeks with the many staff involved would almost certainly fail. Trying to hide the truth from the mother also leads to a risk that she will discover it somehow at a time when her husband is not present to support her. The father’s instinct at this moment is to protect his wife, and the team can help him understand that protecting her from an accidental disclosure helps meet that goal.

It is also possible that gathering more information from the mother’s obstetrician would be helpful to both the father and the team. The team could learn whether there are serious medical concerns about distressing emotions precipitating labor. The father might be reassured if her physician would support disclosure, and a coordination of all care teams could help provide a unified message to the father.

The team should also be aware that a parent’s emotional reaction to a child’s death can shift rapidly over the initial hours. This father’s first response may be a form of denial: He cannot believe that his daughter has died, and he cannot imagine telling his wife. If the team continues to offer supportive understanding of his concern for his wife and unborn child, while sharing their worries about the consequences of withholding information, he may rapidly change his position as he adjusts to the events. Continuing to offer to help him with the conversation may eventually lead him to agree to disclose.

Professor Daniel Groll and Nabina Liebow respond:

Both parents are the daughter’s surrogates. Not only do they have the right to make decisions for their daughter, but they are also entitled to all relevant information about her (including the fact that she died). Consequently, the presumption is that the medical team must ensure that both parents know of her death. This presumption is strengthened by the fact that this particular surrogacy relationship, between loving parents and their child, is about as meaningful a relationship as can exist between people.

Some might think the medical team has discharged their duty in keeping the father informed. After all, until
now he was the conduit through which information to, and decisions from, the family were relayed. And surely this was appropriate.

However, that does not mean that the medical team can now treat the father this way. What made it appropriate to do so before the daughter’s death was that the medical team had every reason to believe that the father was acting responsibly as the family contact by conveying information to and sharing decision-making with the other surrogate, his wife.

But now the medical team has every reason to think those days are over. To accede to his wish would unfairly privilege the father by effectively making him the gatekeeper of what information his wife could access regarding their daughter. Moreover, keeping such significant news from the mother would drastically privilege the father in an unjust way, given the mother’s equal status as surrogate. So there really is a strong presumption that the medical team must ensure that the mother is informed of her daughter’s death.

Are there considerations that defeat this presumption? Here we consider the 3 best candidates: the increased risk of delivery upon learning news of her daughter’s death, the increased risks associated with being born at 28 weeks versus 30 weeks, and information to the effect that the mother wants to be lied to? Often a person’s fears about what is to come may outweigh his concern for his wife, and for his wife to lose the baby. The father’s fears do not.

They might if the situation were different. Suppose the chances of spontaneous delivery were high and the chances of the baby surviving low. Here the medical team might justifiably assume that the mother would prefer not to know of her daughter’s death, in much the same way Nabina can assume that Daniel does not want to be poked in the eye (even though he has not said as much). But our actual situation is one where there is no obvious “default” assumption about what the mother would want.

Suppose, however, the father reports that his view is also hers: Is that reason enough to believe that she wants to be lied to? Often a person’s testimony about what a loved one wants is trustworthy. But we think that there are too many confounding factors in this case to take at face value the father’s word about what the mother wants. Perhaps we would be warrantied in believing that he is expressing her wishes were he able to recall a specific conversation where she expressed a view about what she would want in this situation. Certainly the medical team should try to determine whether the father’s views also reflect the mother’s. Having said that, we believe the bar for justifiably believing that the mother’s view aligns with the father’s is high in this situation. Unless she told the medical team herself in advance what she wanted or the father reported on a conversation he had with his wife about something much like the current situation, we are inclined to think that the bar will not be met.

The important point now is that the medical team does not have enough reason to conclude that the mother would not want to be told, and thus the strong presumption that she must be told is not defeated. By ensuring that she is told, the medical team is not presuming to know what the mother wants. Rather, they are simply fulfilling their obligation.

John D. Lantos responds:

Marriage is complicated. Cross-cultural communication is difficult. And parental grief is complex. This case brings all those domains of complexity together. It is difficult to disentangle them. Respect for the father would require, at the least, that his concerns be taken seriously. After all, the worst possible outcome of this case would be for doctors to override his request, made out of deep concern for his wife, and for his wife to lose the baby. The father’s fears are valid and understandable. That said, they are probably exaggerated in a couple of ways. Given that the mother has been home worrying about her critically ill daughter for weeks, it is unlikely that the news of her death will add greatly to her already highly stressed situation. It is also unlikely that the father and doctors could maintain a charade for weeks without the mother suspecting something. Her fears about what is unspoken may cause more stress than the simple truth.

Honesty may not always be the best policy. There may be situations in which it is appropriate to withhold information to improve outcomes.
CASE RESOLUTION

The oncology and palliative care team met with the father several times that day to work on a resolution. In addition, the palliative care team, with the father’s permission, consulted the mother’s obstetrics physician. Though concerned that physical and emotional stress might affect the mother and possibly put her at a higher risk for preterm labor, the mother’s obstetrician thought that the risk was minimal. In fact, the obstetrician was more concerned that the overall stress to the family, both in the short-term and long-term, may be greater if a discussion of the child’s death was delayed and withheld from the mother. She stressed the importance of maintaining a trusting marital relationship for the unborn child.

The palliative care and oncology teams met with the father and shared the obstetrician’s concerns. All teams involved thought that it would not be appropriate to wait several weeks to inform the mother about the passing of her daughter. They stressed the importance of maintaining a trustful and open relationship within the family to not only help with the grieving process but to maintain a close relationship for the benefit of the unborn child. Counseling continued throughout the day with the father, and although he understood that the risks would not be entirely mitigated, he decided to inform the mother of the daughter’s unfortunate passing. The mother’s pregnancy progressed uneventfully, and she delivered near term (2 weeks after discontinuing bed rest). The family returned home to Bangladesh soon thereafter.

REFERENCES


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