# 4

# Case 4—Aggressive Treatment for a Child's Inoperable Tumor

RK was a four-year-old boy diagnosed with an anaplastic Wilms' tumor (also known as a nephroblastoma), a rare childhood cancer (but the most common pediatric kidney cancer). Approximately 500 new patients a year are diagnosed in the United States, and most are between the ages of 3 and 4 years old. The most common sign is a firm mass in the belly. The tumor expands slowly and is often quite large when detected, but is usually highly treatable. RK's tumor, however, was determined to be inoperable because of its massive size and because it was encasing vital organs. The anaplastic histology (AH) was also prognostically significant[1] (Beckwith and Palmer 1978; Dome et al. 2006). Only about 6–10% of Wilms tumors have the nuclear enlargement, nuclear atypia, and irregular mitotic figures that signal anaplasia, but the prognoses for patients with AH is worse than for patients with more favorable histology.

RK subsequently received aggressive chemotherapy with vincristine and actinomycin-D, and concomitant radiation to shrink the tumor. Despite these best efforts, he succumbed to respiratory distress, and experienced significant weight loss related to loss of appetite. Imaging studies confirmed tumor growth and metastases to his lungs and abdominal lymph nodes.

Upon their son's diagnosis, RK's parents did extensive on-line research about Wilms tumor. Most of the information they found indicated that the disease was highly treatable. However, when their son's physicians talked with the parents at length, over multiple meetings, they explained that there was virtually no chance of RK surviving his disease due to its advanced stage at diagnosis, the unfavorable anaplastic histology, and the metastases to their son's lymph nodes and lungs. Nevertheless, the parents insisted that the medical staff continue aggressive treatment despite knowing the high risk of failure and the harsh side effects that treatment would cause. Side effects from the chemotherapeutic drugs RK received included hair loss, mouth sores, loss of appetite, nausea, vomiting, diarrhea, infections, bruising, bleeding, and extreme fatigue. RK experienced all of these. The nurses would try to tempt RK with popsicles and other small treats, and he would routinely turn his back to them and face the wall.

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RK's parents were of course extremely worried about their son. A phase I clinical trial for Wilms tumor patients became available, and RK's parents immediately consented to have him enrolled.[2] However, after only one experimental treatment, RK was too ill to be included in the study. Several times the parents were approached by the medical team and asked to consider changing RK's care plan from aggressive to palliative. This recommendation was not well received, and the parents instructed the medical staff "not to bring this up again." RK's parents insisted that he wanted to keep fighting. Child Life specialists and social workers were not allowed to work with RK, so it was difficult to assess what in fact RK perceived and wanted. Complicating this case was the fact that the parents were not of the same religion. RK's mother was a Jehovah's Witness, but she had agreed to a blood transfusion for RK at one point. His father tended to rely heavily on non-medical alternative approaches to health care, but in any case, the parents were united in their insistence on aggressive treatment and limited pain medication for their son.

RK's nurses reported that it was clear to them he was in a great deal of pain. When they asked him how he was feeling when his parents were out of his room getting coffee, RK said, "my tummy hurts really bad!" His parents demanded he not be given more than a patient-controlled analgesia (PCA) morphine pump adjusted to administer only the smallest doses. "We want RK to be alert and awake enough to know us and talk to us!" they explained. The parents even refused to allow their son to be given Tylenol, saying, "He doesn't have a fever; he doesn't need it." Nonetheless, it was clear to the nursing staff that RK would be more comfortable if he were given adequate pain medication.

An ethics consult was called in which the futility of continued treatment and the suffering of the child were discussed. It was apparent that the nursing staff members in particular were having a difficult time coping with RK's situation. The suffering and pain experienced by infants and young children is a significant source of moral distress for nurses and other medical staff members who are compelled to provide treatment they believe to be futile or unnecessarily burdensome (Hefferman and Heiling 1999). Lengthy discussions were held regarding the burdens and benefits of treatment, the fact that medical personnel take an oath promising to "first do no harm," and that they believed continuing to provide aggressive care for RK was indeed harming him. The moral distress described by the nurses on the unit resulted in most of them asking to be assigned to RK's care no more than one shift per week, even though many of them were quite attached to him. RK was a personable and friendly child who liked to draw pictures for the nurses and was proud to see his artwork displayed at the nurses' station.

The 90-minute ethics consult resulted in the following options for the continued care for this patient and his family: (1) continue to deliver aggressive medical care and limited pain management according to the parents' requests (and ignore the nursing staff members' increasing moral distress and RK's obvious suffering); (2) have the attending physician present a plan of care that medical staff members believed would be in the child's best interests; i.e., one that would "do no harm," and allow palliative care and better pain management, along with spiritual and emotional support; or, (3) plan for transfer of the patient to another medical care facility where the parents' demands could be better supported. The medical team met with the parents, but they remained unchanged in their insistence that full aggressive treatment and limited use of pain medication be continued. "Palliative care is for dying kids, and that isn't an option of our son! And neither is a transfer anywhere else. He's staying here and we want you to provide every treatment available to help him get better!" they said.

The parents also said their son was to remain a full code, and when he had a seizure five days later, an aggressive response was provided. He was successfully resuscitated, but died within minutes. Shortly after his funeral, the parents divorced. In retrospect, it appeared to the staff that RK was the "glue" that held the family together, and that this explained, in part, the insistence that RK continue to receive aggressive treatment.

## Discussion Questions

1. Did the physicians act appropriately in acceding to the requests of the parents regarding RK's treatment? What about the question of "do no harm?"
2. Could/should the staff have attempted to obtain a court order to stop futile treatment and provide indicated pain medication?
3. Were the parents guilty of abuse of their son?
4. How much say should a minor child, even one as young as four, have in determining his care?

## A Bioethicist Responds

Stories of parents disagreeing with the treatment recommendations of physicians caring for their children may be legion, but this case seems particularly troubling. One can easily imagine the parents' distress, especially after having been told of RK's grim prognosis in view of their son's advanced disease at diagnosis, unfavorable histology and distant metastases; their consent to enroll him in a Phase I trial, even though he was too ill to continue after only one treatment; and their insistence on continued aggressive care in lieu of the palliative care recommended by the medical team. Loving parents not infrequently ask that every effort be made for their severely ill child afflicted with a deadly tumor, but RK spent his last days in a great deal of unnecessary pain, serving only, as it later appeared to the medical staff, to keep his parents together. The existential pain surrounding RK's death that must surely have been felt by those who had cared for him, and who had hoped to help provide a better final chapter to his life, could only have been exacerbated upon hearing of his parents' divorce following his funeral.

Parents clearly bear the legal right and responsibility for their minor children, including the consent, or refusal of consent, to medical treatment for them. This right and responsibility may also be viewed as a freedom, as it seems to have become in the U.S., where a parent's adherence to particular religious teachings can come into play; Jehovah's Witnesses and Christian Scientists are examples of such.

Members of these faith traditions will generally opt for faith-based approaches to health care, either by consulting practitioners within their faith communities, or solely as individuals relying on faith alone, rather than for care provided by state-licensed physicians. Judges may grant exemptions to established law designed for the protection of minor children, such as not requiring standard and indicated medical care for a very sick child in need of that care, when parents refuse it on religious grounds, if the parents can show evidence to their practice of faith healing and provided this practice is established within the parents' religious tradition (Merrick 1994). The issues surrounding parental refusal of treatment recommendations for their minor children, religion, parental rights, suffering and/or child endangerment (at least from a health care team member's perspective) and law have never been adequately settled, and there is little evidence that they will be any time soon (Woolley 2005).

Hickey and Lyckholm attempted to deal with this problem through examination of several twentieth century cases, concluding that, "The right of a sick child to appropriate medical care supersedes the right of a parent to withhold that care for the sake of religious beliefs. The refusal of medical treatment on behalf of minor children is only supported when (1) the effectiveness of the treatment is in doubt, (2) the burdens of treatment outweigh its benefits, and/or (3) the care is refused by a decisionally capacitated minor" (Hickey and Lyckholm 2004, 273). However, their recommendation that members of the healthcare community inform themselves about the doctrines, previous court cases and current laws of major religious groups prohibiting medical treatment still leaves physicians, nurses and others unequipped to deal with anyone like the parents of RK whose beliefs led them to demand futile and burdensome treatment for their son. Diekema (2004) suggested that the *harm* principle might provide a more appropriate threshold than the *best interests* standard most frequently invoked to challenge parents' rights to make medical treatment decisions for their children. Other writers have attempted to offer guidance to improve communication, understanding, and trust building (Kon 2006), as well as guidelines for conflict resolution (Pinnock and Crosthwaite 2005). Yet all of these authors reluctantly concluded that should parents refusing treatment for their children prove to be totally intransigent, with the children at risk of serious harm, the only remaining option may be to address the courts. The legal system is rarely an elegant or efficient vehicle for resolving medical treatment disputes. If the court had been involved in RK's case, it is quite likely that the parents' right to demand continued treatment would have been upheld. No judge wants to limit parental decision making and wake up to see a headline describing the state's complicity in "killing" a child against the parents' wishes.

Clinicians are also certainly wary of finding themselves in adversarial positions with families, and perhaps nothing could open that possibility faster than involving the courts. Yet, as Alessandri writes, "On rare occasions, judicial involvement is necessary, and it should be undertaken as a non-adversarial process so that the possibility of rebuilding the relationship with the family remains." (Alessandri 2011, 631). There have certainly been times when a more forceful approach has been required, such as the rather dramatic case reported in Britain several years ago where a High Court judge found it necessary to make a 15-year-old girl a ward of the court in order to save her life and also to ban her mother from visiting the girl in the hospital *pro tem* until her daughter's condition had stabilized (Dyer 2014).

The foregoing offers a very brief overview of some of the most pertinent literature on this subject, but it adds little in the way of hope to the already sad narrative of RK's final days. Curiously, a very similar case occurred several years prior to RK, where a 6-year-old girl, KM, was admitted to the hospital with an advanced Wilms tumor. Her parents were advised of her terminal condition and that only palliative chemotherapy would be appropriate in her case. Her parents refused all analgesia for their daughter except for ibuprofen with a small amount of codeine with acetaminophen; they maintained that KM was not in pain and held to their concern that opioids were addictive and would cause sedation, thereby decreasing KM's ability to interact with her family. Several complex factors seemed to shape KM's parents' behaviors, including their denial of their daughter's prognosis and their misperception of opioid therapy (Weidner and Plantz 2014). KM's parents held fast, refusing to allow the administration of opioids for pain until her last hour of life, when she asked for medicine to help her breath and said she was ready "to go to heaven." Her parents then agreed to a small dose of an anxiolytic that provided sedation, and she died soon thereafter. Weidner and Plantz conclude their piece, as have others, that in the absence of a negotiated compromise, the invocation of Diekema's *harm principle* and the enlistment of a child protective agency (i.e., the Courts) is the way to go. Still, one cannot help but wonder why either KM's or RK's terrible agonies had to go on for as long as they did.

We know a bit more here about the case of RK; perhaps, therefore, it is easier to understand how the complex dynamic that developed between the parents, their son and his oncologists as one group, and how other groups such as palliative care, Social Work and Child Life, came to be seen as adversaries of the first group, most especially by RK's mother. She is easily perceived as a fearful, aggressive, manipulative woman capable of taking control of an entire healing enterprise that is oriented toward maximizing the good of the sick person, and her primary focus is upon her own needs such that she succeeds, ironically, in ensuring that far more harm than good is brought to her son. Laying blame solely at her feet for the sad ending to RK's story would be fruitless, however, particularly since she was never going to be swayed; she simply would not engage in order to avoid discussion entirely, or she would respond in passive-aggressive ways, as she did after the formal ethics consult, which was just another way for her to maintain control over the entire situation. The mother in this case was most likely unaware of what was really going on inside her, and in any case the real locus of control was not within her but rather within the health care professionals surrounding her and her family.

The problem with those health care professionals, however, is that they did not take proper and effective control of RK's situation at an appropriate moment. This should probably have been done at the time the mother refused to allow any further conversation about palliative care and/or most certainly when she began insisting on the limited dosage of pain medication for RK. It is understandable that one medical practice is unlikely to intrude on the "turf" of another if they are ever to function well again on other cases, so palliative care would not have been expected to challenge pediatric oncology. There are perhaps others in the hospital who could have intervened when it became apparent that things were simply not going well for a particular patient, and among them are none better equipped than nurses.

Nurses generally feel they are powerless, especially in the presence or in the shadow of physicians, whose orders and instructions they have been taught to follow explicitly, and who, they have also been taught, outrank them. Likewise, their professional mores include holding family members in the same respect as patients. Nurses today are frequently the ones to call ethics consults, but they are not the ones likely to demand much more than that if they see situations like RK's that warrant further attention. Any member of the health care team should be able to request a palliative care consult; such consults should not be able to be refused by either family members or the attending physician. Nurses should feel greater empowerment; they should be made to feel that they will be respected for the medical/scientific expertise that they possess, and they should not be afraid to speak up as advocates on behalf of patients. Nurses should be assured that if they act and speak truly for the patient's good, they will be supported for it, even if they are the ones to push for serious discussion or reluctantly ask that the Courts become involved. This should obtain for other members of the health care team as well, be they therapists, technicians, aides or whoever may have integral roles to play in the welfare of patients. Creating a safe environment wherein this kind of conversation can happen will undoubtedly call for something of a culture change in many health care institutions requiring significant time and effort, but such time and effort might be remembered as minor investments if the number of cases with outcomes like KM and RK declined appreciably.

## A Health Communication Scholar Responds

The death of this little boy, about whom we know little other than that he was very sick and liked to draw pictures, was complicated by obvious and apparently insurmountable communication difficulties. There are other troubling aspects of this case as well.

It seems possible that there was a delay, maybe a considerable one, between the time RK's parents might have felt something was wrong with their son and when they sought medical counsel. In his recent book about his daughter Zoe's diagnosis and treatment for Wilms tumor, Elisha Cooper recounts that the day after he discovered a lump on Zoe's side, he and his wife took her to New York-Presbyterian Hospital for immediate diagnosis and treatment (Cooper 2016). RK's mother was a Jehovah's Witness and his father was described as preferring natural or alternative methods of medical care. When they discovered the lump on RK's side, did they first try herbal or alternative treatments, or did they ignore it and hope for the best? Did it go unnoticed for some period of time? Perhaps they immediately sought medical treatment despite having different preferences for their own health care and it was unfortunately the case that RK's cancer had already metastasized. The case narrative makes it clear that both parents were united in their insistence that RK continue to receive aggressive treatment, including remaining a full code, despite whatever other differences of opinion might have characterized their relationship, parenting styles, or willingness to seek medical treatment.

It is also noted that RK's parents did extensive on-line research about Wilms tumors after their son was diagnosed. Wilms tumor was named after Max Wilms, a German doctor who wrote one of the first medical articles about the disease in 1899.[3] In Zoe Cooper's case, an imaging study revealed the Wilms tumor on her kidney to be Stage III, and even though there were complications during her surgery, which required the removal of the tumor, her kidney, and part of her colon, the surgeon reassured Cooper and his wife that Zoe had "a good cancer." Zoe's parents were reassured that after 22 weeks of chemotherapy and targeted radiation therapy it was "going to be okay." Searches for information about Wilms tumor almost immediately present the good news about long-term survival rates. According to the St. Jude Children's Research Hospital website[3] long-term survival rates are excellent: about 85–90% of Wilms tumor patients with *favorable histology* (like Zoe) can be cured. Cure rates for patients with *anaplastic histology*, (like RK), a more aggressive form of Wilms tumor, are lower. Dome and colleagues reported survival estimates for patients with Stage I anaplastic Wilms tumors as 69.5% (four-year event free survival) and 82.6% (overall survival). For patients with favorable histology, survival estimates rose to 92.4% (four-year event free survival) and 98.3% (overall survival) (Dome et al. 2006). Were RK's doctors able to describe the significant difference tumor histology made in survival rates? Despite the medical team's best efforts, perhaps RK's parents chose to believe instead the hopeful news about Wilms tumors on various pediatric cancer websites and therefore insisted on treatment on their son's behalf. And what are we to conclude about RK's parents' insistence on limiting his pain medication, despite his obvious discomfort?

Bluebond-Langer (1978) wrote an insightful book based on her dissertation research with leukemic children that provides a useful theoretical framework for beginning to understand RK's parents' insistence on continued aggressive treatment. Bluebond-Langer would likely say that RK's parents knew their son was dying, and equally important, RK knew he was dying. RK knew his parents knew, and his parents thought RK probably knew too (but they hoped he didn't, since no one had told him). And both parties were determined not to let on to the other. Bluebond-Langer described this as *mutual pretense awareness*, a concept borrowed from Glaser and Strauss (1965), who described how the behavior of a dying patient, including his or her interactions with others, could best be understood by the "awareness context" in which it took place. An awareness context is the context within which people interact, including what each knows of the other's situational cognizance and status.[4]

Bluebond-Langer's work with leukemic children demonstrated that mutual pretense awareness was the dominant mode of interaction between the dying child and his or her parents because it offered a way to do what society expected of them. The child could act as if he or she had a future, for which children are supposed to prepare. Parents could maintain their responsibilities for protecting and nurturing, which become very difficult in the face of a child's terminal illness. Their decisions not to reveal their awareness to one another reflected their knowledge of the social order into which they had all been socialized. The child and parents used mutual pretense to protect one another—the dying child did not want to make his or her parents sad or give up on a future, and the parents did not want to feel they had not adequately protected their child.

Bluebond-Langer demonstrated how dying children gradually became aware of their changed relationship to their social worlds, including their relationships with their parents. The children she observed and talked with passed through stages of understanding their disease and how sick they were, and eventually understood they would not get better and would die, even if in the past they had relapsed and recovered. The children she observed would make references to their impending deaths through their conversations and play in the presence of medical personnel or non-family members, but would maintain an impenetrable silence with their parents. Once the child recognized death was imminent, most did not play with toys very often, and when they did, their play usually involved references to death and disease. For example, they would put dolls or toy animals in graves. Sedentary activity, like coloring, increased, but the range of themes expressed tended to decrease. Most pictures dealt with destruction, storms, fires, graveyards, and religious images, even among children who were not raised in a religious faith.

Children's comments about the future also changed once they had this awareness of their impending death. For example, one 5-year-old boy wanted his Christmas presents in October, and in June several children asked whether they could prepare to go to school in September. Even the doctors in Bluebond-Langer's study who doubted children could know their prognosis without being told thought these actions showed the children were suspicious, perhaps even probing for information, about how long they had to live. Some dying children also started to refuse to comply with procedures and tests, and when the nurses would relent, that further reinforced the children's ideas of how close they were to dying. How could medical procedures be overlooked, when formerly they were so important to the child's recovery?

RK and his parents appeared to conform to the contextual boundaries and rules of mutual pretense awareness, one of which is to avoid "dangerous" topics, including the child's level of pain. More pain means sicker, and sicker means closer to dying. RK may have felt comfortable telling the nurses that he was in pain when his parents were not in his room, but admitting that in front of his parents would spoil the illusion that he was feeling no different than he was previously, when he was not as sick. Similarly, insistence on continued treatment also signaled no change in prognosis; continuing treatment as usual signaled RK's status had not changed.

It is also quite possible that RK's parents acted selfishly in insisting on prolonging his life, and that their consistent refusal of pain medication for their son was to enable him to interact with them so they would not have to interact with one another. Surely the finality of losing a child, especially if his death might also end a marital relationship, is something most people would want to postpone. Guilt over delaying treatment or imposing their own preferences for medical treatment on RK (to the extent that either happened) might also have motivated decisions to do everything possible to prolong their son's life. We cannot know for sure, but the concept of mutual pretense awareness offers at least another possible explanation for otherwise inexplicable behavior. We do not know the inner dynamics of families whose every interaction and decision occurs under the harsh glare of the medical gaze. We can, however, continue to advocate for the well-being of patients, while simultaneously extending forgiveness and understanding to parents and family members who do not always act in ways that minimize our moral distress or conform to our ideas of a good death.

## Notes

[1] Anaplastic is a term used to describe cancer cells that divide rapidly and have little or no resemblance to normal cells. In 1978, Beckwith and Palmer published a detailed histopathologic review of Wilms tumors that were collected on the first National Wilms Tumor Study (NWTS-1). Approximately 6% of the tumors had cells with nuclear enlargement, nuclear atypia, and irregular mitotic figures, and were considered to have anaplastic histology (AH). The presence of anaplasia was prognostically significant; 44% of patients with AH died as a result of disease, whereas only 7.1% of patients without anaplasia, the so-called favorable histology (FH) subtype, died as a result of disease.
The more recent fifth National Wilms Tumor Study of 2596 patients with Wilms tumor who were enrolled onto NWTS-5, found 11% of tumors to have anaplasia (AH). Four-year event-free survival (EFS) and overall survival (OS) estimates for assessable patients with stage I AH (n = 29) were 69.5% (95% CI, 46.9–84.0) and 82.6% (95% CI, 63.1–92.4). In comparison, 4-year EFS and OS estimates for patients with stage I favorable histology (FH) were 92.4% (95% CI, 89.5–94.5) and 98.3% (95% CI, 96.4–99.2) (Dome et al. 2006).

[2] Clinical trials are conducted in a series of steps, called phases, each of which is designed to answer a separate research question (Mahipal and Nguyen 2014).

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| **Phase I** | Researchers test a new drug or treatment in a small group of people for the first time to evaluate its safety, determine a safe dosage range, and identify side effects. |
| **Phase II** | The drug or treatment is given to a larger group of people to see if it is effective and to further evaluate its safety. |
| **Phase III** | The drug or treatment is given to large groups of people to confirm its effectiveness, monitor side effects, compare it to commonly used treatments, and collect information that will allow the drug or treatment to be used safely. |
| **Phase IV** | Studies are done after the drug or treatment has been marketed to gather information on the drug's effect in various populations and any side effects associated with long-term use. |

[3] For more information, see St. Jude Children's Research Hospital website: https://www.stjude.org/disease/wilms-tumor.html

[4] Bluebond-Langer's work is based on Glaser and Strauss' earlier work that described how the behavior of the dying patient, particularly in interaction with others, can best be understood in terms of the "awareness context" in which it takes place. An awareness context is "what each interacting person knows of the patient's defined status, along with his recognition of the others' awareness of his own definition…. It is the context within which these people interact while taking cognizance of it" (Glaser and Strauss 1965, 10). Glaser and Strauss identified four types of awareness contexts, one of which is mutual pretense awareness.

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